The Independent Living movement paved the way: Origins of personal assistance in Sweden[1]

Adolf Ratzka, Independent Living Institute, 2012

Benign oppression
Social policy is rarely made by the people whose lives it affects. Rather, it is formulated based on political considerations by politicians and bureaucrats who, by necessity, have limited knowledge of the conditions of other people's lives – especially regarding those of us with extensive disabilities who depend on other people to survive and require practical assistance with activities of daily living such as getting out of bed, dressing, personal hygiene and bathing. The greater our dependence, the more others assume they are entitled to have opinions about our needs and the less those of us affected have a say in how we want to live our lives and what social resources we need. As a result, solutions and services often make us more dependent on others rather than independent.

In most countries, the obvious lack of material resources relegates us to a limited and undignified existence, forced to depend on the kindness and charity of others. Even in Sweden, official statistics show that we are second class citizens.[2] However, the mechanisms that generate dependence are far more subtle in Sweden. The low expectations, overprotective attitudes and limited opportunities for autonomy in daily life and life projects that we encounter cause many of us to experience dissatisfaction, frustration and quiet despair, without knowing why.

One's home as an institution
Until the 1990s, people in Sweden with extensive disabilities had little choice with respect to daily support and housing solutions. The only available options for someone who required help with getting out of bed, dressing, personal hygiene and bathing were the family, a group home or a cluster housing apartment.[3] Few people managed to live alone with just community-based home helper services. Granted the large institutions had disappeared – at least for people with physical disabilities – but instead the home had become an institution. Community-based home helper service and cluster housing personnel made most of the decisions related to daily life, what tasks could be carried out and how long the colloqually-called "home samaritans" ("hemsamariter") could stay (Ratzka, 1982). They could also take decisions about one's furniture, such as bed height, and the time the user was to go to bed – older people sometimes had to go to bed before 5 p.m. in summertime with an evening snack beside the bed.[4]

The terms "home" helper and cluster "housing" service underscore that assistance is provided in the home and that the services are not intended to promote recipients' ability to assume their rightful place in family and society on equal terms with others regarding work, leisure, social relations, building a family and travel. "Home" helper and cluster "housing" services essentially meant house arrest for people who needed physical assistance throughout the day, regardless of location.

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[1] translated and adapted from Ratzka, A. "Independent Living-rörelsen banade vägen", kapitel 2 Perspektiv på personlig assistans, Peter Brusén, Karin Flyckt (ed.), Gothia Förlag 2012

[2] *Alltjämt öjämlikt!* (Still Unequal). The National Board of Health and Welfare report (2010) shows living conditions for persons with disabilities.

[3] This form of housing called in Swedish *boendeservice* involved 10-15 municipally owned rental units dispersed throughout one or several ordinary apartment buildings, with large kitchens and bathrooms, and access to shared staff. *Boendeservice* was preceded by "*Fokus*" or cluster housing, provided by municipalities in the 1960s.

[4] For a definition of an institution, see Ratzka, A., *Independent Living and attendant care in Sweden: A consumer perspective*, World Rehabilitation Fund, New York, Monograph No. 34. 1986 internet publication

Most notably, users had no right to refuse to accept help. In her poignant poem “It was the first time we met and I was very shy,” Annika Jacobsson described an encounter in her cluster housing apartment in the 1980s with a young man who helped her to undress, wash and change her sanitary pad.[5] The motto was “all go to all,” which in a cluster housing facility in Stockholm meant that users had to deal with up to 67 different staff members each month.[6] Because the system entailed sharing staff, users had to accept help from people with whom they might not get along and women were forced to accept help from men. As one woman at a conference in the 1980s said, “it was only when I had home helper services that I did not have any control over which men entered my bedroom.” If a user asked for certain employees too often, or socialized with them in their spare time, there was a risk that the supervisor could transfer the involved employee to another district. The idea was to maintain a professional relationship so that the home helper or cluster housing service user would not be able to “take advantage of” the situation.

Many employees in the cluster housing and home helper services were also unhappy, with high absenteeism as a result. The other employees had to take over the duties of those who were absent, which often meant there was only time for assisting with what the staff considered to be most necessary. In a municipality that I studied in 1987 I found that clients’ needs had been assessed at 20 percent more home helper hours than the municipality had budgeted for, which implied that the social service department had not intended to deliver all the services that the clients needed. One convenient way to achieve these savings was to not replace sick employees (Ratzka, 1990). At that time, the employer did not have to pay sick pay, which meant the municipality actually saved money when employees called in sick.

Patchwork solutions

People with extensive disabilities require daily practical assistance with many tasks. In the 1980s in Sweden, several different authorities shared responsibility for providing assistance services. While users of the services might not have seen any difference between going to the toilet at home, at work, at school or while running errands in town, the responsibility for assisting clients could be divided among up to six or seven authorities: the municipality’s home helper services; its cluster housing services unit; the county council's home nursing service (hemsjukvård) in municipalities where toileting was classified as a medical intervention; for disabled persons who worked the county council’s Labor Board (länsarbetsnämnden) paid employers for providing that assistance; assistance services at school (elevassistans); the assistant services board at the university (styrelsen för vårdartjänst); or the municipal escort service (ledsagarservice).

The authorities had each their periodic needs assessments, administrators, phone hours for booking services and long lead times. For example, users must book escort services at least one week and transportation services at least two days in advance. Fitting together the puzzle pieces of daily life required considerable time and energy, as well as planning and organizational skills, a high frustration threshold, and advanced social skills. Staff working for these public monopoly services knew that we users had no choice and treated us accordingly. Most users only managed to arrange support for the most pressing needs and whenever possible refrained from subjecting themselves to the often humiliating treatment.

The probability of a breakdown in the service chain increased with each additional service that the user depended on, since problems and delays could occur at every link.

At a conference in Stockholm in 1986 a woman living in a cluster housing unit related how she had lost two work days earlier that week. Due to high staff absenteeism in her cluster housing unit she had a new assistant who was unfamiliar with her morning routine. When the special transportation service knocked on the door she was still in bed. Since the transportation service could not wait and since

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[5] Ibid., for a critical assessment of cluster housing and home helper services in the 1980s.

[6] STIL held a contest in 1985 where the winner, the disabled person with the highest number of staff – it was 67 – in one month, won a season ticket to Skansen Zoo in Stockholm, where the baboons, according to a newspaper report, decided which caregivers could enter their cage. The winner was to learn how the monkeys achieved that degree of self-determination.

rides had to be ordered at least two days in advance she had no choice but to take sick leave or a vacation day.

When life is fragmented into many pieces over which the individual has no control, a sense of powerlessness and exclusion develops, along with resignation. It becomes difficult to see one's life as a whole for which oneself is ultimately accountable. Without the ability to plan for the future, there is no future.

These solutions had been gradually developed over the years by social services officials, politicians and disability organizations, which at the time mostly consisted of non-disabled elected representatives and functionaries. Home helper services, cluster housing units and group homes did indeed significantly improve quality of life compared with the large institutions, which were being phased out at the time (but that to this day exist in many other countries). Still, Swedish disability policy in the 1970s and 1980s contained many special solutions that led to and perpetuated the marginalization of our group, limiting our opportunities for full participation in society. Self-determination over our body, daily life, home and life projects determine our opportunities for education, career, earnings, social relationships and family formation. Compared with the degree of self-determination that other citizens take for granted, we were second class citizens then – and still are today.

A look from the outside

In 1973, I arrived in Sweden as a 30-year-old researcher with my electric wheelchair, ventilator, single and in need for practical assistance from others in daily life. I came from Los Angeles, where I had attended the University of California, Los Angeles for seven years. In 1966, I had moved to California from Munich, Germany where I had lived in an institution for five years after having contracted polio in 1961. After five years in an institution, where the staff had regulated my daily life in great detail, even when it came to toilet visits, it was not easy for me to manage the almost overnight transformation from patient[7] and object of care to subject and boss. In Los Angeles, I was the one who hired, trained, scheduled, supervised, paid and motivated fellow students who helped me with personal needs, household chores, and other tasks. Without any role models[8], it took several years of trial and error, mistakes and small successes before I felt reasonably in control of my assistance situation. The money for my assistants' salaries, through an unbureaucratic *ad hoc* solution, came from the government of the State of Bavaria.

In Sweden, I was fascinated by a paradox. On the one hand, I found a highly professionalized welfare society with income re-distribution and tax-financed services designed to reduce welfare inequalities. On the other hand, many people with extensive disabilities lacked education, work, commitment and social relationships, which they saw as a natural result of their disability. In California, where the social safety net was nowhere near as developed as in Sweden, I had many friends with extensive disabilities in the young Independent Living movement – people with an appetite for life who studied or worked, became involved in civic affairs and employed personal assistants with direct payments from local authorities (Ratzka, 1982).

I found an explanation of the Swedish paradox when the money from my research grant ran out and I needed to use municipal home helper services myself. In this way I acquired first-hand experience of yet another way to solve the needs of people with extensive disabilities – a lesson I paid for with severely decreased self-determination (Lundeqvist, 2002). The experience enabled me to compare institutional living, home helper services and what I would later call personal assistance, based on their respective impact on the user's self-perception and quality of life.

The Independent Living movement paved the way

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[7] The Latin root of "patient" means to wait and suffer.

[8] Only years later I met other disabled persons, residents of California, who had similar arrangements. California legislation enabled counties to either provide In-home Support Services in kind or pay equivalent amounts to persons who hired their, what was then called, personal care attendants.

The Independent Living movement[9] was launched in California in the early 1970s by a few individuals with extensive disabilities who needed assistance with the activities of daily living. They viewed themselves as a civil rights and self-help movement, inspired by the struggle of blacks and other groups for equal rights, and were committed to work for self-determination and against over-protection, paternalism and outright discrimination.[10]

Internationally, the movement was to become a major force and contributed to the UN Convention on the Rights of Persons with Disabilities (2006) with the paradigm shift from patient to citizen that the Convention represents, the Convention's language and especially with Article 19, which enshrines the right to live included in the community with self-determination.[11]

Locally, the Independent Living movement works in self-help groups, often called Centers for Independent Living, which soon spread across North America, as well as to other continents. As a typical self-help movement it offers peer support meetings for people with disabilities. Participants at these meetings – people with disabilities only - share information, tips and tricks of the trade, experiences and insights to support and learn from one another. In this way, they benefit from the mistakes and successes of others in situations such as hiring and supervising personal assistants. These meetings enable participants to learn how we internalize our surrounding's often subtle overprotective and paternalistic attitude towards us, how prejudices can easily become self-fulfilling prophecies and, ultimately, how we can encourage one another in the individual transformation and liberation process. Peer support helps us to understand that we are not alone with our problems, that "there is nothing wrong with us" and that we can support each other in assuming greater responsibility for our lives and taking our rightful place in family and society.

> According to the Independent Living movement, we must first make demands on ourselves. We cannot demand that others view us as people of equal value, as ordinary citizens who share an equal need for respect, recognition and love – if we do not do so ourselves (Ratzka, 1988).

Characteristic for this civil rights and self-help movement are the following principles:

- de-medicalization (we are citizens, not patients)
- cross-disability (the common experience of discrimination unites us, diagnoses separate us)
- de-institutionalization (phasing out institutions including "mobile" institutions which run our lives)
- de-professionalization (we are the foremost experts on our needs)
- self-representation (we must speak on our behalf, individually and collectively). (Ratzka, 2003)

The movement's most important demand is that people with disabilities must have the same degree of self-determination and freedom of choice that others take for granted. Since we are the foremost experts on our needs, it is our responsibility, individually and as a group, to take the initiative and develop, test and spread solutions that make us more independent. The movement's message is best grasped by people with extensive disabilities who depend on daily help from other people and who are therefore most vulnerable to overprotection, control and paternalism.

One of the prerequisites for achieving self-determination and freedom of choice with responsibility, according to the Independent Living philosophy, are cash payments for the purchase of goods and services that persons with disabilities might need in compensating their disabilities. Cash payments enable individuals to either become employers and hire their personal assistants or become customers and buy goods and services in a market, instead of having to accept services in kind provided by a monopoly. Consequently, cash payments for personal assistance are the corner stone in the Independent Living movement's strategy for empowerment. Cash payments are viewed as the

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[9] For a definition of Independent Living, see Wikipedia

[10] For a vivid personal experience of the early Center for Independent Living in Berkeley, see Kleinfield, Sonny. Declaring independence in Berkeley. 1979 online publication

[11] Article 19 – Living independently and being included in the community. United Nations Convention on the Rights of Persons with Disabilities. online publication

most important tool for phasing out institutions of every type, stationary and mobile (such as home helper services).

From supply-driven services and powerlessness

The crucial difference between personal assistance on the one hand and home helper services and institutional care on the other is that personal assistance is demand-driven and the other services are supply-driven. In the case of supply-driven services, the provider (in Sweden often a municipal government) has a budget that covers the costs of a certain number of employees' work hours. The provider allocates the staff among the residents, based on the provider's moment to moment assessment of the residents' needs. Users are often forced to wait when the staff considers other residents' needs more urgent. An individual, for example, might want to shower, or invite friends over for a home-cooked meal, but would have to wait until the cluster housing staff were not busy with a neighbor or a staff meeting.

Typical for supply-driven services is that users have no alternative, but must accept what is offered – supply-driven services are often provided by monopolies. In the Stockholm of the 1980s the only solution for users dissatisfied with their municipal home helper or cluster housing services was to move to a different neighborhood or municipality. In an effort to simplify the provider's administration, supply-driven services usually consist of a fixed bundle of services where users cannot substitute one ingredient for another. For example, users could not continue to live in a cluster housing apartment, if they did not use the staff there. Service providers bundle the service package based on their assumptions about the needs of the target group, aiming at an imaginary average. All users are therefore forced to accept the same service according to the "one-size-fits all" principle, even though people with disabilities are just like other people in that they differ from each other regarding individual abilities, tastes, interests, family circumstances, age, occupation, disability, needs and aspirations. For example, cluster housing facilities in Stockholm only have one or two bedroom apartments, but no single-family houses; the Social Services Department had apparently not expected that people with extensive disabilities would want to have children or a garden.[12]

Toward demand-driven services and consumer power

In contrast, demand-driven services rely on a market in which many sellers use pricing and quality to compete for customers. A variety of differentiated services are offered, aimed at different groups and niches within the target group. Competing services offer freedom of choice and accelerate innovation and development. Demand-driven markets require customers with purchasing power. However, in many cases new money is unnecessary. For example, the public funds that would have been used to cover home helper and cluster housing services can be converted to cash payments that go directly to the users. Such a solution is referred to as "direct payments". The money follows the user, not the provider. The solution empowers consumers and, at the same time, creates incentives to offer services that are in demand. It also increases freedom of choice and mobility regarding location and type of housing – the opportunity to live alone, as part of a family or collective, in a rented apartment, a condominium or single-family home. Direct payments also allow those who prefer to do so to become employers and hire and pay their assistants. This option gives users the best opportunity to shape their assistance solution to meet their particular needs and desires, while granting the greatest possible control over service quality.

Demand-driven services improve opportunities for self-determination and thus can lift the user from the powerlessness that often accompanies supply-driven services. Instead of wasting their energy and becoming frustrated and bitter about fruitless attempts to influence the hierarchy of home helper or cluster housing services, direct payments enable users to convert that same energy into something positive, such as customizing one's very own personal assistance solution. Feedback is immediate in the form of improved quality of life, for instance, when the user can undertake a trip abroad with a good assistant hired for that purpose. Users can learn from their mistakes and celebrate their successes. To supervise others is not easy, but can be very educational. Gradually regaining control of

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[12] For a discussion of supply-driven services, see Ratzka: "User control over services as a precondition for self-determination." Plenary lecture at the Danish EU Presidency Seminar on "Quality of Life and Quality in Services for People with Disabilities," Oct. 31 –Nov. 1, 2002. Online publication

our bodies and our lives enables us to strengthen our self-confidence and helps us to achieve a more positive outlook on life.

Based on these thoughts, in the early 1980s I began to contact people who used home helper or cluster housing services, wrote articles about the problem, presented foreign models and launched the concept of direct payments for personal assistance in Sweden (Ratzka, 1982). I proposed national level financial responsibility and direct payments from the tax-funded national social insurance system (Försäkringskassan) to enable users to hire personal assistants or purchase assistance services from providers.

> The current Disability Allowance (handikappersättningen) could be increased to include the cost of the personal assistance needed because of physical disabilities. The assessment must cover all situations where personal assistance is needed: not only the tasks that municipal home helper services traditionally provide, but also the assistance necessary to take one's responsibilities in the family, assistance in education, at work, during leisure time and on vacation, when going places in town or travelling abroad, for interpretation or reading. (Ratzka, 1986)
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> By receiving money from the state directly into our hands, we would have the purchasing power at our disposal to create a market for these services, where different companies would compete with each other. The customer would contract one or more companies and switch as needed. Or users could organize their personal assistance the way we plan to do within the STIL project. (Ratzka, 1986)

Personal assistance is born

The concept of personal assistance entails that the assistance user, as the assistants' employer, decides who works for him or her, with what tasks, when, where and how. The definition was later expanded to include situations where the user, as customer, hires the services of a personal assistance provider. Crucial in both solutions is that individuals must be able to choose the level of control and responsibility over their service that suits them best at a given time, and that users must be able to customize the services based on individual needs, abilities, circumstances, preferences and aspirations. (Ratzka, 2004)

"Personal" in "personal assistance" does not refer to the fact that assistants might work with intimate physical tasks such as personal hygiene – the local government's home helper services had also helped us in the shower. The crucial difference is in the political dimension of "personal," which entails individualization in decision making and the concentration of power to one person – the user, since the money would follow the user, not the provider. This arrangement empowers the users to be in charge and shape the organizational and administrative design of their services according to their individual circumstances: to decide just how much operational responsibility they are prepared to assume, the number of assistants to whom they will allocate their assistance hours, to choose which assistants would be invited into our private lives, homes and families to provide household help, assist us with our bodily needs, assist us with the physical aspects of raising small children, and accompany us to school and work, to visit friends, during leisure activities and when we travel.

This approach creates demand-driven services - our purchasing power attracts service providers who compete by adapting their services to our individual needs. In supply-driven services, providers do not compete and have no incentive for offering customization, since its additional organizational effort would not be rewarded by higher sales - clients are forced to take whatever is offered to them. Also, an incremental, gradual conversion of supply-driven services to achieve the same degree of self-determination as demand-driven services is an illusion, since the difference in quality depends on who has the purchasing power (Ratzka, 2011). No mobile institutions à la home helper services, no one-size-fits-all solutions could be called "personal assistance."

1983 conference – an important starting point

In December 1983, I took the initiative to an international conference in Stockholm, where speakers included Ed Roberts and Judy Heumann, key figures and friends from the IL movement in the US, who presented the ideology and approach of the Independent Living movement.[13] The conference was the first of its kind in the Nordic countries. One of the many themes of the conference was the contention that people who are dependent on daily practical help from others must be the employer or supervisor of their personal assistants to achieve self-determination over their body and lives. Representatives from the established disability movement opposed this notion - most of them did not need personal assistance themselves. The Swedish disability movement had long struggled for more effective municipal home helper and cluster housing services by demanding more information and training for the personnel. Their position was that all change must occur within the existing municipal structures. (Ratzka, 2003)

Representatives of the traditional disability organizations found it difficult to understand that cooperation on equal terms between residents and staff is not possible in a supply-driven system where services are based on hierarchical structures and top-down central planning. They did not view the worker-resident relationship as a function of the unequal division of power. They also felt it was society's responsibility to work out solutions to the problems. A few commented that personal assistance might be appropriate for the individualistic American tradition, but not the Swedish welfare state tradition “where we have collective solutions to care for each other”.

Despite this resistance, a small group of conference participants who needed home helper services or lived in cluster housing units continued to meet regularly after the conference under my leadership – without representatives from the established disability movement – to formulate a personal assistance solution for themselves and others.

The pilot project

In spring 1984 the group formed a nonprofit organization and called itself the Stockholm Cooperative for Independent Living (STIL). Under the bylaws, only people who need personal assistance are eligible to become members and board members. Over the next couple of years, I developed a proposal for a pilot project with about 20 participants. Most administrative jobs within the project would be reserved for people with disabilities. The purpose of the pilot was to test privately-run consumer directed personal assistance. Stockholm municipality would engage STIL as service provider for STIL members who were currently receiving municipal home helper or cluster housing services. The cooperative would function as employer of the assistants with all the concomitant legal responsibilities and delegated all other tasks to the individual cooperative members, such as recruitment of assistants, wage negotiation, training, scheduling and supervising their respective personal assistants. The goal was to enable the individual assistance user to have maximum self-determination with a minimum of administrative work.

As a subcontractor to the municipality, STIL would receive compensation per hour corresponding to the municipality's current average hourly cost for home helper services in the user's home. Thus, the STIL model would not entail any added costs for the municipality, but increased quality for the users. Our “sales argument” was “better quality for the same cost.” As a nonprofit organization, the cooperative had no owners who'd benefit from any profits. Any excess income would be reinvested in the organization in the form of training, peer support groups and development projects for members and others who wanted to improve assistance services, both within and outside Stockholm County. (Ratzka, 1992)

Originally, personal assistance was mainly intended for people with physical disabilities, but the solution soon proved adaptable to people who, for other reasons, need assistance with their daily activities. One participant in STIL's pilot project was a young man with Down's syndrome whose mother helped to supervise the people who assisted him in daily activities by interpreting for her son. “Deputy Supervisor”, “co-supervisor” or “service guarantor” are titles for the role in which one or more people who assistance users trust complement their ability in supervising their personal assistants. This role is often filled by a family member, legal guardian, assistant or someone employed by the assistance provider.

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[13] Sveriges Television producer Marianne Gillgren interviewed Ed Roberts and Judy Heumann in conjunction with the conference (January 1984). Video, online publication

Most of STIL's members were skeptical about hiring assistants who had a background in medical professions such as nursing. Nurses typically train in institutional settings, such as nursing homes or hospitals where patients are at the bottom of the hierarchy – an attitude which we didn't see as the ideal preparation for a job where the assistance user is the boss. Moreover, nursing homes and hospitals are usually supply-driven services without the conditions to meet the individual patient's needs and preferences, neither organizationally nor in terms of resources—the polar opposite of our definition of personal assistance. But most importantly, we did not see ourselves primarily as healthcare recipients and preferred to focus on our healthy sides whereas nursing education focuses on the sick. In the case of disabilities caused by an ongoing illness we insisted on the right to the same degree of self-care which non-disabled persons with illnesses take for granted, the difference being that our assistants under our direction would assist with self-care. The limits to this approach become however evident in persons with multiple disabilities including cognitive or psychiatric conditions that require the person who provides assistance to possess specialized knowledge. (Ratzka, 1988)[14]

Within the STIL project we would test our concept of personal assistance and develop administrative solutions as arguments and in preparation for a national reform, which was one of our aims.

> To be able to live in any municipality with the same quality of life, so that we would not be serfs in our municipalities, the responsibility for financing must be as centralized as possible – at the national state level. But for us to have the greatest possible control of our assistance, responsibility must be as decentralized as possible – with the individual user. (Ratzka, 1986)

STIL promoted the proposal in newspaper articles, interviews and conferences for almost three years. At the same time, the cooperative prepared its members for their future tasks as personal assistance users and as supervisors of their personal assistants through peer support groups at frequent regular meetings. Based on my own experience as an employer and supervisor for my personal assistants in California after a five-year institutional stay, I was aware of some of the difficulties that our members could encounter.

One important preparation was self-assessment of our individual needs of personal assistance. Before we were ready to face the municipality's social workers who would assess our personal assistance needs, each project participant was to do his or her own assessment. We needed to come to a realistic estimate of which activities we would want to engage in provided we had the proper personal assistance. Need for assistance we did not want to express as a number of interventions during the day, but as the average number of hours per day spread over one year. However, most members found it difficult to estimate how many hours they would need to manage their daily lives in a dignified manner, to study or to work, to spend time with family and friends, doing errands in town, going out and traveling. For many people the question was utterly hypothetical, because they always had to rely on someone else to take the initiative for doing something together. Together we compiled checklists with duties and chores that we knew other "ordinary" people might do and estimated how long things might reasonably take. We also practiced in role play the recruitment process, as well as conflict situations we might encounter as supervisors. Above all, we reminded each other of the "model little cripple" within all of us who wants to please others and not rock the boat, who is malleable, easily satisfied and would not dare to demand the living conditions that others take for granted.

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[14] More about education and professionalism can be found in Ratzka: *Independent Living and attendant care in Sweden: A consumer perspective*, World Rehabilitation Fund: New York. Monograph No. 34. 1986:43, online publication

Picture 2:1 Our model little cripple: grateful, kind, simpleminded, easy to care for and easy to administer – and still not a member of STIL - Based on the German original “Unser Musterkrüppelchen”, cover for Behindertenkalender 1981 by Ernst Klee und Gusti Steiner, Fischer Verlag, 1981.

Building the system

We started our pilot project in January 1987. Before and during the pilot project we had to solve many administrative and organizational questions, without any role models of similar activities. We had assistance from a lawyer from the Cooperative Development Center and a mentor in the person of Folke Carlsson, head of Styrelsen för vårdartjänst (a government agency for supplying disabled students in higher education with housing and assistance services) who also was a personal assistance user. We needed to formulate and negotiate agreements regarding the division of responsibilities and money flows between the municipality, the cooperative and the individual member.

Stockholm's Social Services Administration wanted to integrate our solution into their regular activities offering us workplace and salary for a full-time administrator, in addition to the payroll costs for our assistants. However, we were not interested in having the municipality in control of our activities, expansion and direction of development. Instead, we demanded a flat fee for each produced hour that would cover all costs, including salaries, administration and overhead, as well as training activities and development projects. We wanted to develop the service with our own generated funds with minimal dependence on the municipality. The solution that we wanted to formulate and test was also to serve as a model for a national direct payment system for personal assistance which we proposed.

The flat fee would be equivalent to the municipality's costs for home helper services in the user's home including travel time between users, administration, overhead, training and more. But the accounting system used at the time by the municipality was unable to calculate their cost per hour. In the end, STIL had to submit an estimate of the hourly cost of municipal home helper services so that the politicians could make their decision. (Ratzka, 1993)

Many of the rules and procedures we developed during the pilot project were adopted in 1994 by the national social insurance system (Försäkringskassan) and incorporated into the regulations of the Act concerning Support and Services for Persons with Certain Functional Impairments (LSS). These rules and procedures consisted of the needs assessment as number of hours spent with the user (instead of number of interventions or monthly lump sums), payment from the municipality one month in advance, accountability of use of funds and reporting through assistants' signed time sheets, a twelve-month period during which the individual user could save and move around funds and hours, and a flat rate per average assistance hour that included a budget covering administration and overhead, training of both assistance user and assistants, expenses for accompanying assistants in town or when traveling, as well as assistants' technical aids for the job.

The cooperative's decisions were often preceded by endless discussions during our open board meetings, usually attended by all members who had the opportunity to speak their minds. The process was extremely time-consuming, but yielded results. The solidarity in supporting each other and in promoting our goals was strong. We'd all turned out when we staged rallies or stopped the traffic in rush-hour streets in support of individual members who ran into problems with the municipality. We knew that many eyes were upon us and that the future of the STIL model as a solution for others depended on how well each of us handled our newly acquired freedom under responsibility. (Ratzka, 2003)

STIL becomes a political force

We succeeded in generating media attention around the STIL project. STIL became a political force in the debate of the 1980s concerning the division of roles between the state and the individual in welfare production and the question of who is better positioned to ensure maximum welfare.

According to political scientist Bo Rothstein, this topic was already under discussion within the Swedish Social Democratic Party in the 1940's (Rothstein, 1988). At that time, influential Social Democratic politician Alva Myrdal advocated the "in-kind line" where the state owns enterprises through which it produces goods and services, such as appropriate children's clothing that is distributed in state-run stores. The in-kind line concept is based on skepticism about the ability of the people to determine their own needs. In contrast, then Minister of Social Affairs Gustav Möller advocated the cash line, in which the state strengthens the purchasing power of its citizens through the social insurance system (Försäkringskassan) so that they can meet their own needs. "The basic premise was that the citizens themselves knew what they needed" (Rothstein, 1988). And indeed, Möller's cash line won with respect to the general pension.

The Left Parties argued that “only a strong public sector guarantees general welfare” and portrayed us as advocates of privatization. From that direction we were viewed as unsuspecting victims of Thatcher-inspired right-wing politicians who wanted to dismantle the public sector. We tried to avoid winding up in either political camp – we needed support from both sides. We replied the mainly non-disabled ideologists on both sides that we supported a society based on solidarity in which the tax-funded sector is responsible for needs assessment, exercise of public authority and financing of these services. We expressed our skepticism that the state would be the best service provider, backed by our own extensive first-hand experience.

> The STIL model is a way to replace the municipality's monopoly as service provider. STIL demands alternatives and competition in service provision but wants society to retain its responsibility for financing the services.” (Ratzka, 1990)
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> ... certain decisions must remain private regardless of political system, such as when and how I want to go to bed when I am tired. With all due respect to parliamentary democracy, when I need to go to the toilet the decision-making process must be decentralized and awfully quick. (Ratzka, 1993)

The Swedish Municipal Workers Union strongly opposed the proposal that assistance users function as employers and supervisors for their staff. They feared that we would ruthlessly exploit their members and treat them as “nineteenth-century maids.” This resistance did not begin to taper off until the early 1990s, when sufficiently many generations of assistants and even research supported the conclusion that our assistants’ working environment was twice as good in psychological and physical terms as their counterparts’ working in the stressful home helper and cluster housing service settings, where staff were unable to choose the clients for whom they worked. (Ratzka, 2003)

Many mid-level officials in municipal social services routinely felt they were responsible for us and were dubious about our ability to become employers and supervisors. Or possibly they may have felt their own role was coming under threat. Nevertheless, some officials shared our dynamic view on skills acquisition and personal development agreeing with us that the majority of assistance users could grow into these roles with time and with the support of the cooperative.

In general, most people including the established disability movement found it difficult to view assistance users as supervisors or employers of their assistants, as was already pointed out. Well-meaning politicians and journalists had long presented our group as the “weakest of the weak" that society was morally required to take care of and protect. This image had never been questioned since Sweden had never had any widely-known and visibly capable people who happened to need personal assistance. The image had also been internalized by the assistance users themselves, especially by those who had received help from the established disability organizations in their socialization as people with disabilities. These organizations promoted semi-institutional solutions such as cluster housing. In Sweden, employers are viewed as the pillars of society. To suggest that “the weakest of the weak” could be employers entailed turning the entire social pyramid upside down.

We received ideological assistance from several directions. Parent-run day care centers had already begun to supplement the municipal monopoly with their private cooperative solutions. Developments in then Eastern Europe, where the disadvantages of the central planning economy had become increasingly apparent by the late 1980’s, also helped our cause – supply-driven home helper and residential services can be viewed as elements of a central planning economy. Since the pilot project would be run as a cooperative, we played in the same league as the great popular movements HSB, Riksbyggen, Fonus, Folksam, KF, Arla and others (cooperatives for housing construction and condominium ownership, insurance, supermarkets, farming). In retrospect, the choice of a non-profit organization in cooperative form was crucial to STIL’s success. The democratic cooperative movement’s traditional emphasis on education, combined with the by-laws restricting membership to assistance users, resulted in opportunities for mutual learning and support among peers. At the same time, we avoided the discussion of how any surplus in the business would be used – we saw so much in society in need of change and that work would require resources. We could not anticipate the personal assistance market that would arise 25 years later with an increasing market share in the hands of a few large-scale profit-maximizing enterprises.

The most important support came from the Swedish Liberal Party and its chair Bengt Westerberg, who contacted us in autumn 1986 after reading about our initiative in the media. He referred to our project on several occasions in Parliament, including at the public policy debate in February 1987, as an example of social-liberal solutions with self-determination under responsibility, which his party wanted to promote.

Making the STIL model permanent: the path to LSS

In 1989 – after two years of the pilot project dedicated to system building, internal consolidation, member education and publicity work – we felt strong enough to conclude the pilot project. At that point we requested the Stockholm's Central Social Welfare Board to take a decision to make the STIL model permanent so that STIL and other entities with the same concept could become a subcontractor for the city. The alternative would have been to continue on a small scale for years. But thanks to many requests for help from friends in other parts of the country, we knew that thousands more could achieve the same boost in quality of life if they had the opportunity to try our solution.

The highly contentious ideological battle over privatization occurred in a social climate that was overshadowed by the overt decline of the Central and Eastern European economies, and by a strong distrust of private solutions. Stockholm's Central Social Welfare Board finally approved our proposal by a single vote majority at a meeting in June 1989. After the decision the path was open in the City of Stockholm for anyone who wanted to join STIL or any of the other cooperatives or businesses that would establish operations.

With Stockholm as a model, friends in other municipalities now had a better starting point, aided by STIL, when requesting the same solution locally. In the true Independent Living spirit, STIL helped its friends in other parts of the country to start independent local cooperatives. We did this by spreading the concept, free of charge, including by-laws, rules, procedures, and administrative tools, providing management training, supervisor training, and soft start-up loans. (Ratzka, 2003)

Over the following years, STIL's membership and operations snowballed – agreements with several neighboring municipalities were signed and members poured in to the extent that our accounting department almost collapsed. Supervisor courses were offered to everyone – regardless of whether they joined STIL or started a new organization. STIL helped to found the European Network on Independent Living (ENIL) where I served as the first chairperson. The network gave us a great opportunity to spread Independent Living and personal assistance as a tool to replace institutional solutions both within and outside Europe. As a long-term commitment to development and dissemination, at my initiative, STIL and GIL (Gothenburg Cooperative for Independent Living) founded the Independent Living Institute foundation in 1993 as a national and international think tank dedicated primarily to self-determination and personal assistance.[15] (Ratzka, 2003)

1994: Direct payments for personal assistance as legal right in all of Sweden

In 1989, the Social Democratic government appointed a commission to identify and analyze the living conditions of people with disabilities. The purpose of the inquiry included developing proposals on how to improve conditions for people who depended on practical help from others in daily life. The group's precarious situation had received national attention, in part because of STIL's work. In 1991 a non-socialist government came to power with Liberal Party leader Bengt Westerberg as Deputy Prime Minister and Minister for Social Affairs. In these positions and based on the commission's inquiry, he was able to propose and get Parliament to vote for legislation that introduced the legal right to direct payments for personal assistance from the national government's tax-funded social insurance system (Försäkringskassan). The Act came into force in January 1994 in the midst of a national financial crisis and at a time when European Union entry requirements on national government finances resulted in

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[15] For a description of STIL's situation, activities and projects, as well as the purpose of the Independent Living Institute in 1993, see "*Hemtjänst i omdaning – möjligheter och svårigheter i decentraliseringens och privatiseringens tid.*" (Home help services in transformation – opportunities and difficulties in a time of decentralization and privatization), documentation of STIL hearing Stockholm 1993. Independent Living Institute.1993 with appendices, online publication

burdening local governments with many budget items previously financed by the national government. In retrospect, the reform, which added to the state budget what were once municipal expenditures, must be viewed as the result of Bengt Westerberg's strong personal commitment to the issue.

Minister for Social Affairs Bengt Westerberg said at a conference in 1993:

> Just over six years ago, I came into contact with STIL, the Stockholm Cooperative for Independent Living. I talked about that meeting at the Parliament's public policy debate in February 1987. STIL had described itself as a civil rights movement for people with disabilities. "We are tired of non-disabled people deciding over our lives. We want the same freedom and the same responsibilities as others," Adolf Ratzka, one of the founders of STIL, said to me. Instead of municipal authorities providing assistants, carers or helpers in various contexts, STIL wanted a system in which those who wish to do so themselves could hire their own assistants. The idea was actually quite obvious, I said in my statement to Parliament. The person who needs service should be able to set the requirements and shape it. And I also dared to aspire to a vision: eventually, all people with disabilities who need personal service should have the same opportunities as Adolf Ratzka and his friends to hire their own assistants.
> Little did I know then that I would be the person to propose that reform in a bill to Parliament. It is with great pleasure that I can conclude that my vision – which naturally has also been shared by many others – is on the way to becoming reality. The Act concerning Support and Service for Persons with Certain Functional Impairments (LSS) will provide thousands of people with serious physical disabilities with the right to personal assistants. It is a great success for the civil rights movement that Adolf Ratzka and his team launched here in Stockholm seven or eight years ago.[16]

20 years after the personal assistance bill passed Parliament Bengt Westerberg traced its origin and evaluated his legislation in his keynote at a social welfare research conference in Los Angeles:

> The roots of the personal assistance concept are actually here in Los Angeles and California. The person who launched the idea in Sweden is Adolf Ratzka.[17]
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> In 1986, I met Adolf Ratzka and his colleagues in STIL for the first time and was enthused by their ideas.They managed to convince the local authorities in Stockholm County to let them run a pilot project. The funds the authorities had been ready to spend on community-based services for Adolf and the others in STIL were put at their disposal to be used as they desired. This allowed them to employ, train and supervise their own personal assistants and to decide with what, where, when and how their assistants should work. This project started on January 1, 1987.
> At the time, I was still part of the parliamentary opposition. In a speech in parliament a few weeks later, I recounted my meeting with STIL members and expressed my vision that their project would provide a prototype for disability policy reform in Sweden.
> Not everyone was as enthusiastic. Many even opposed the idea, among them representatives of the disability movement as well as professional social workers. Still, the idea was interesting enough for the government to ask the commission reviewing the disability policy to investigate. The commission shared my view and came up with a proposal to introduce personal assistance. That is how it became part of the 1993 disability reform.[18]

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[16] Westerberg, B. (Minister for Social Affairs at the time) at the conference on LSS which was held by among others the National Board of Health and Welfare in Stockholm on May 26 1993, as quoted in ”*Hemtjänst i omdaning – möjligheter och svårigheter i decentraliseringens och privatiseringens tid*.” (see above)

[17] Westerberg, B. “Personal Assistance - a revolution for people with disabilities”, Keynote at **7th International Conference on Social Work in Health and Mental Health, University of Southern California, Los Angeles, June 26, 2013,** online publication

[18] Westerberg, B. ibid.

> … for thousands of Swedes, the right to personal assistance has meant a freedom never before experienced — a revolution for those with the most significant impairments. This does not mean that their lives have become easy. We cannot eliminate their disabilities. What we can do is partly compensate for them.[19]

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[19] Westerberg, B. ibid.