

International Encyclopedia of Rehabilitation

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Center for International Rehabilitation Research Information and Exchange (CIRRIE)

515 Kimball Tower

University at Buffalo, The State University of New York

Buffalo, NY 14214

E-mail: ub-cirrie@buffalo.edu

Web: <http://cirrie.buffalo.edu>

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Personal Assistance in Sweden

Ulla Clevnert, BSc, Social Work
Senior Administrative Officer
Social Services/Disability Issues
The Swedish National Board of Health and Welfare
Tel: 075-247 31 04
Växel: 075-247 30 00
ulla.clevnert@socialstyrelsen.se

Lennarth Johansson, PhD
Psychologist, Associate Professor in Gerontology
lennarth.johansson@socialstyrelsen.se

Personal assistance is a unique and individual tailored support programme, which makes it possible for people with severe disabilities to choose their own way of living, that is, “to live a life as anybody else”, as it is phrased in the Swedish disability policy. It secures rights and equal opportunities for recipients to make choices concerning their own lives and to have their wishes respected. It has increased opportunities for recipients to live on their own or with family, to study, to work, and to participate in community life. Overall, personal assistance has enhanced the quality of life for people with severe disabilities as well as for their families (Clevnert and Johansson 2007).

This description of personal assistance is designed in Sweden. But some form of personal assistance is now available in all Nordic countries, most Western European countries, Australia, parts of Asia, the U.S. and Canada. The naming of personal assistance may vary from country to country, which is often related to legislative categories. The organization of service and the degree of user control varies around the world and may be affected by the administration of payments, employment laws, etc. The following shows how personal assistance programs and assistance allowance are designed in Sweden.

The Swedish Context

Public policies and programs providing health care and social services, as well as pensions and other forms of social protection are comprehensive in Sweden. The intent is for financial security and social rights to be guaranteed to all citizens including children, the elderly and people with functional impairments.

A well developed social insurance system and pension system means that nobody has to abstain from service and care due to economic reasons. Having a majority of women in the labor market necessitates a formal system of care for the elderly, children, and people with disabilities. The basis of this policy is a tax system in which all taxpayers contribute, for the good of all according to capacity. Public services are almost totally financed by taxes. The user pays only a fraction of the costs (some 4-5%). The biggest share of the costs (about 82-85%) is covered by local taxes. National taxes cover the remaining costs of services and care.

There are three levels of government. The state or the national government is responsible for laws and legislation, questions of social insurance and general planning. The 21 county councils or regions are responsible for health care, rehabilitation and assistive devices. Finally, at the local level, the municipalities (290 in all) have basic responsibility for

education, housing, childcare and social services. The fact that health care and social services are primarily funded by local taxes confirms the independent role of the local authorities, that is, their independence of the national government.

The national government defines the objectives of activities, but municipalities and county councils enjoy great freedom to decide on the quality and nature of the measures undertaken. The social services and health and medical services are governed by framework laws that specify the framework and objectives. Within this framework, the municipalities and county councils can interpret the law and shape their activities according to their own priorities.

According to *the Health and Medical Services Act* (1983), the aim is good health and equal access to health services for everyone. Rehabilitation and assistive devices for people with functional impairments are obligations regulated in the Act. *The Social Services Act* (1982) regulates that the municipalities have ultimate responsibility for ensuring that all residents in the municipality obtain the support and help they need. The municipalities have a special responsibility for people with physical, mental, or intellectual functional impairments so that they are able to live in a way that corresponds to their needs and to play an active part in the community.

Swedish Disability Policy

Swedish disability policy is based on the principle of universal equality of dignity and rights and to achieve full participation and equality. This means that almost all children with disabilities grow up together with their parents and brothers and sisters. They are in childcare while their parents are working just like other children, but the family can support in many ways. Young people in Sweden move from their parents when they have finished school. The situation is the same for young people with disabilities, but they perhaps move to housing with special service or have support by personal assistants.

One factor of importance for the development of disability policy is the deeply rooted tradition of popular movements in Sweden. The organizations of disabled people work as pressure groups in relation to society; they are important consultative partners, and they have often shown society how to arrange services. They support science, research, and development. The Swedish organizations of disabled people are run and dominated by people with functional impairments. The organizations receive financial backing from the state, county councils, and local authorities for their activities as political interest groups.

The Disability Reform

In 1994, the Disability Reform came into force. One vital part of the reform was *The Act concerning Support and Service for Persons with Certain Functional Impairments, the LSS* (a Swedish acronym) (Regeringen 1993a).

The LSS Act extended the rights of people with functional disabilities and aimed to assure persons with severe functional impairments individualized support and good service according to needs. The fundamental principles and the qualitative requirements of the Disability Reform and the measures in the LSS can be summarized as: self-determination and influence, accessibility, participation, continuity and a holistic approach.

The LSS has extended the rights of people with functional impairments. This is not a framework law. Instead, LSS is very much a human-rights statute.

The Act applies to people

- with intellectual impairments or autism,
- who have received brain injuries as adults with a consequent impairment of their intellectual capacity, and
- who have great and permanent physical or mental functional impairments that cause considerable difficulties in daily life and consequently require considerable support and service.

The LSS gives people with severe functional impairments the legal right to ten different measures of support and service that shall secure good living conditions for the individual. The measures shall be adapted to individual needs; they shall be lasting and coordinated and easily accessible. One of the measures for which one can apply are personal assistance but other examples are: companion service, foster homes and special housing for children and young people, housing with special services for adults or daily activity programs.

All measures received under the LSS are free of charge for the individual. This means that the individual doesn't pay for the personal assistance. But there are some exceptions. If one lives in housing with special services, one must pay the rent for one's own flat and costs for food and other personal expenses, but the individual will not be paying for service and support from staff.

Personal Assistance and Assistance Allowance

One part of the disability reform was the introduction of personal assistance and assistance allowance. Previous to that time people with extensive needs of assistance did not get the necessary service through the home help services. A large number of persons had no influence over the help they received. Often, the help was carried out by a large number of home helpers coming in and out of the recipient's home. There were also people who had to live in institutions or in hospitals because they could not get the proper support in their homes.

The personal assistance program was created following models from the Independent Living Movement, started in the U.S. during the 1970s as a popular force for people who needed daily help. The purpose was to struggle against what was experienced as over-protectiveness and paternalism.

The right to personal assistance can be granted based on two pieces of legislation, The Act LSS and *the Assistance Benefit Act*, or LASS (a Swedish acronym) (Regeringen 1993b).

Assistance allowance is intended to make it financially possible for people with severe disabilities to appoint a personal assistant, on their own or through a provider, to create support as far as possible adapted to the individual and to optimize the person's influence over how the support is arranged. This is often achieved, for example, by the person him- or herself being the assistant's supervisor.

Financing

The responsibility for personal assistance and the assistance allowance is divided between the municipality and the state. The state is represented by the Social Insurance Agency. If assistance is required for 20 hours a week or less, the municipality provides the cost for the assistance. A person who needs assistance applies for it at the Social Service Office. If a

person needs assistance for basic needs for more than 20 hours a week, he or she applies for it at the Social Insurance Agency. The municipality will carry the cost for 20 hours, and the state, through assistance allowance, is responsible for the remainder of the hours of assistance.

The municipality and the Social Insurance Agency must co-operate so that a person gets proper assistance; the municipality is ultimately responsible for seeing that people who need assistance get it.

The reason for personal assistance coming under dual responsibility is purely administrative, so the state and municipalities share costs.

Eligibility

Not everyone entitled to support and service according to LSS is entitled to personal assistance or to assistance allowances. There are certain conditions that make an individual eligible for personal assistance. The person must have *basic needs of assistance* in daily life, such as help dressing/undressing, assistance with eating and personal hygiene or assistance in communication. If one needs assistance with those fundamental or basic needs, one has also the right to assistance with other daily life activities, such as shopping and leisure-time activities. Both children and adults can have personal assistance. A person must be younger than 65 years of age when getting the assistance for the first time.

When reaching age 65 or older, the person can keep the same number of hours that he or she was granted, but the number of hours cannot increase. If the recipient needs more help, he or she can have additional help through the regular home-help services.

If a person applies for personal assistance and the municipality or the Social Insurance Agency does not grant the support, or does grant it, but with fewer hours than needed, the person can appeal to a court. This is a means for a person to get a second and legal opinion. The court has the right to change the decision made by the municipality or the Social Insurance Agency.

Use of Personal Assistance and Assistance Allowance

At the end of 2006, approximately 3,700 people had personal assistance according to LSS and approximately 14,100 people had assistance allowance according to LASS. Some 4 % of the total number of recipients had personal assistance according to both LSS and LASS. (Socialstyrelsen 2008 a). Out of the total number of persons receiving personal assistance, 53 % were men and 47 % woman. In the population as a whole, about 1.7 per thousand had personal assistance. The number of persons with personal assistance and assistance allowance has increased every year since 1994 and was at the end of 2008 about 18,000 persons. (Socialdepartementet 2008).

The assistance allowance is granted in the form of a number of hours of help, per week. The assistance includes the number of hours needed for a person to have his or her *basic needs* provided for, as well as for *other personal support*.

There is no ceiling; that is, the number of hours can theoretically be unlimited where people with severe injuries or impairments need more than one assistant at the same time. Some recipients have personal assistance 24 hours a day, which makes it possible for those with severe impairments to live on their own.

In 1994, the average number of hours was 65 hours per week and since then, the number of hours has increased and was 108 hours per week in 2008.

Administrative Routines

The assistance allowance from the Social Insurance Agency is paid directly to the recipient so that he or she can employ one or several assistants. The person can also turn to the municipality for the service, to an assistance company, or a co-operative. If the recipient wants to have the service from another source, he or she can have the money paid directly to the provider. If the recipient is the employer, he or she cannot employ someone in his or her own family who is living with the recipient. If a man, for example wants his wife as personal assistant, he must turn to the municipality, to a company, or a co-operative so that his wife can be employed as his personal assistant. About 50% of the recipients with granted assistance allowance have the personal assistance provided by the municipality; 12% turn to co-operatives; and about 34% choose companies or other organizations. Less than 4% employ the personal assistants themselves.

The assistance allowance shall be used for the employment of personal assistants and it is 247 Swedish kronor (SEK)/hour (2009), equivalent to 35 U.S. dollars. The level of reimbursement (SEK per hour) is decided by the government annually. This amount is the salary for the assistant, as well as costs for administration, recruiting, introduction, additional training, and expenses for the assistant, for example costs for tickets when going by bus or to a movie, together with the recipient. The amount of payments is independent of income or assets of the recipient, his or her spouse, or other family members. Regardless of who is providing the services, they receive the same payment from the Social Insurance Agency.

Personal Assistant Workers

A personal assistant can be described as a personal aid who does all that a recipient is unable to do because of functional impairments. The personal assistant can compensate for lack of mobility, loss of sight, or intellectual impairment. The assistance is given in different situations and locations by a limited number of personal assistants. The recipient has the right to decide **what** the assistant should do and **when** and **how**. The personal assistant shall assist with the basic needs in one's home as well as provide assistance in society, at work, meeting with family and friends, on vacation, etc.

There are no national statistics on the personnel working as personal assistants. However, it has been estimated that some 70,000 persons annually (during 2006 – 2007) were working as assistants. About 80 % of these were women and 20 % men, which is the expected proportion as in most caring professions in Sweden. Some 25 % of the assistants were family members of the recipients (Socialdepartementet 2008).

Those working as personal assistants have various education and training as well as background experience. There is no formal training or certification required for personal assistants, and many have no training. There are high school level courses as well as some university courses available for those who want to work as personal assistants. It is also common that personal assistants are offered on- the -job skills training through their employers (Socialdepartementet 2008).

To be an assistant requires personal maturity, as well as, the ability to imagine oneself in another person's situation and the willingness to do what the recipients would otherwise do for themselves if they had no impairments. The special professionalism needed is an ability to

understand and practically fulfill the recipient's intention. There are different opinions about training for personal assistants. Some recipients do not want assistants who are trained for nursing, instead they argue that personal assistants should be chosen, trained and managed by users themselves or by their representatives. Other recipients may want assistants with nursing training, e.g. those who have medically complex needs. Obviously, the kind of training the assistant requires depends on a number of circumstances.

A Review of the Assistance Allowance

Service provision is not regulated regarding, for example, competence and supervision; there is no license requirement for those who are providing personal assistance. To address these and related issues, the government commissioned a Parliamentary Commission to describe, analyze, and suggest solutions by the year 2007 (Socialdepartementet 2005).

The Commission initiated in 2005 a study to capture recipients' views on how the assistance was provided, their freedom of choice, whether they had changed care providers and their opinions about possibilities to influence how the assistance services are provided. A questionnaire was sent to a random sample of recipients. Out of a total number of 12,200 persons receiving assistance allowance at the time, 915 persons were addressed. The response rate was 74%. Results indicate that 70% of the recipients had the opportunity to choose from among more than one provider. There were differences between groups: 60% of those who had the municipality as provider reported that they had opportunity to choose their provider; 93% of those with private companies as providers had been able to choose. Almost 60% had been able to decide on which assistant they wanted to be assisted by. The possibility to change provider is an important issue regarding freedom of choice. Among all respondents, over 40% reported that they had changed provider at least once.

Sixty-five percent of respondents reported that they could decide their assistants' tasks, that is, what they wanted help with at a particular time. Again, there was a difference between groups: 90% with personal assistance by co-operative, compared with 55% of those with personal assistance by the municipality, could decide their assistants' daily tasks. Another question addressed whether the help received was tailored to the recipient's needs and wishes. Almost 60% confirmed that the assistance was tailored to their personal needs. More than half of those participating in the study confirmed that they themselves had the "final say" regarding the help and services they received. There is a pattern throughout the study indicating a higher degree of satisfaction among those using private or cooperative providers, compared to those using public providers. However, on the whole, nearly 90% of the recipients were "very satisfied" or "rather satisfied" with the personal assistance.

Though the reform has been in effect for over decade, there is still little research evidence and empirical data available. In a review of current state of the art of knowledge in 2005, some issues and problems have been pointed out (Socialstyrelsen 2005). The review indicates a built-in paradox. On the one hand, the possibility of receiving extensive services and care creates the opportunity to lead an independent life, even for people with severe disability. On the other hand, because of the extensive services, there is an increased dependency on personal assistants. The quality of the relationship between the recipient and the personal assistant is of crucial importance for the recipient's feeling of independence. This tension is visible, for example, among young recipients who are in school, who are sometimes torn between the assistance focused on school work and their desire to engage in social contacts and leisure activities.

An interesting experience that has been noted is that disabled people with assistance allowances, who are capable of expressing their own will and wishes, often prefer personal assistants who are not specifically trained in caring work. Rather, assistants with other types of occupational background and experiences are their first choice. This could be interpreted as an expression of independence and a desire to distance oneself from being identified as a “nursing object” needing care.

Another type of tension has to do with crossing the boarder of family privacy. Needing round-the-clock support implies a great openness on the part of the family for “other persons” being in the home. The personal assistant also faces this tension, being “a guest” in the home of the recipient and his or her family. Given these circumstances, it is easy to understand that there could be role conflicts between being “a friend” or “a carer.” The risk for role conflicts is, of course, attenuated when the personal assistant is a family member. Then, different expectations related to being a parent, a spouse, a care giver, and being employed at the same time can lead to problems that ultimately could have repercussions for the person with impairment.

In a Cochrane review of research on personal assistance, commissioned by the National Board of Health and Welfare, few controlled studies of personal assistance were found. However, existing evidence suggests that personal assistance is generally preferred over other services by the recipients. The results indicate that personal assistance probably has some benefits for some recipients, their friends and families. Further, the reviews indicate that personal assistance is safe, though it may be difficult to manage. People who choose to receive personal assistance may prefer it to other services, particularly services over which users have little control. Personal assistance appears to benefit informal caregivers as well. On the other hand, the reviews do not indicate that personal assistance would be superior to other services for people who are already satisfied with the support and services they already receive (Mayo-Wilson et al. 2008 a-f).

Costs

The costs of personal assistance and assistance allowance have increased, year by year, and more rapidly than expected. Between 1995 and 2004, the costs increased some 15 % annually. The reasons behind this development are twofold: First, the number of recipients has steadily increased, and second, the average number of hours of help and support has also increased. Further, the fact that since 2001, recipients can keep the assistance allowance after 65 years of age has added substantially to costs (Riksförsäkringsverket 2004). The total public costs amounted to 22,9 BSEK in 2008. The costs incurred for the municipalities was 6,9 BSEK and national government 16 BSEK. The total costs corresponds to 0,7 % of the 2008 Gross Domestic Product in Sweden.

When studying personal assistance based on an economic analysis from a societal perspective the assistance reform has led to great improvements for persons with extensive functional impairments and for their next of kin. The reform aimed to secure rights and equal opportunities and the cost increase is partly due to the success of the reform. A considerable portion of the costs and the cost increase for the assistance allowance is due to a redistribution of costs for other support systems. If the personal assistance did not exist, this would have consequences not only for the recipients and their families, but also for other support system and actors. Then, there is a risk of poorer coordination, duplication of costs and lower cost effectiveness (Socialstyrelsen 2008 b).

Discussion

The personal assistance reform has increased the opportunity for people with severe disabilities to choose their own way of living, that is, “to live a life as anybody else”, as it is phrased in the Swedish disability policy. Personal assistance secures rights and equal opportunities for recipients to make choices concerning their own lives and to have their wishes respected. With a personal assistant, recipients have the right to decide **what** the assistant will do, **when** he or she will do it, and **how** it will be done, as well as from **whom** the recipients choose to have the assistance. It has increased opportunities for recipients to live on their own or with family, to study, to work, and to participate in community life. Overall, personal assistance has enhanced the quality of life for people with severe disabilities as well as for their families.

Given over 15 years of experience of the assistance allowance, one can also identify some unresolved problems and issues related to the reform. For example, even if the goals of personal assistance are simple and clear, the rules and statutes that regulate the assistance are somewhat troublesome. Due to the complexity of its design, personal assistance has caused certain problems of implementation for the municipalities and also for the Social Insurance Agency. Statutory rules and administrative routines have been successively altered in order to clarify matters of responsibility, to improve implementation, and to curb the heavy expenditure of the state.

However, there are prevailing problems, such as increasing overall costs, training of personal assistants, and working conditions in general. Furthermore, there is no system for monitoring and supervising personal assistance provided by organizations other than the municipality. Service provision is not regulated regarding, for example, competence and supervision. There is no license requirement. A Parliamentary Commission was authorized in 2004, to review and analyze these shortcomings. In a white paper, the commission suggested that supervision and monitoring of personal assistance should be a part of the national supervision, and that license should be required to providers of personal assistance. The proposal also means that the national government should have the responsibility for decisions on eligibility and financing of personal assistance.

The assistance allowance creates possibilities to receive extensive services and care that enhance the opportunity for recipients to lead independent lives. A person with severe disabilities will be greatly dependant on support and help from others. Such dependence can imply a tension between the recipient and his or her personal assistants. The quality of the relationship between recipients and their personal assistants is therefore important. The fact that the recipients can decide on the recruitment and the additional training of the assistants, gives the recipient greater control and say over the relationship.

The fact that one can keep the assistance allowance after age 65, can create inequalities between those who received the assistance allowance before age 65 and those who are not eligible due to the age-ceiling. Further, the group being granted assistance allowance is privileged compared to other groups of elderly needing services and care. The family caregiver, for example, benefits from receiving the services via the assistance allowance, unless of course, the family caregiver is the personal assistant. The difference, then, is that the spouse, for example, will have the caring responsibilities but is being paid for this, as compared to those not being granted the assistance allowance. On the other hand, if the spouse is not one of the personal assistants, he or she will still have to carry an increased responsibility, due to age-related increasing need for help. There is no direct- payment system

for people caring for a frail elderly family member. On the other hand, elderly persons needing service and care have a legal right to receive necessary help.

So far, issues related to aging with the assistance allowance have not been subjected to public debate, as the number of persons with disabilities surpassing the age of 65 receiving assistance allowance is low. However, it is easy to foresee that there can be problems in the future. For example, should there be an age-limit for being a personal assistant? If the care needs of recipients with disabilities increase due to the over-lay of frailty in later aging, will the public provide the necessary services and care?

Another consequence of the current development is that the number of persons applying for assistance allowance has increased among those 60 to 64 years of age, thereby adding to increasing costs. The opportunity to “keep” the assistance allowance as the recipient ages illustrates that even reforms with good intentions can create increased inequalities between groups of dependent persons. On the other hand, the fact that there are older people receiving assistance allowance and, thereby extensive help, could tentatively open doors for a similar system in the old age care system in the future.

To conclude; the personal assistance and assistance allowance is widely recognized as a great improvement in the life quality for people with severe disabilities. This conclusion is supported by findings in the Cochrane review. However, there are still problems needing attention. One set of problems is of an administrative nature, requiring review of the accessibility of the assistance allowance. Another problem has to do with the availability and training of the personal assistants. There is also a recognized need for a system for monitoring the quality of the assistance allowance. Finally, the increasing costs call for new cost containment strategies. However, costs in measures and programs supporting people with severe disabilities, need to be viewed in a broad perspective, which often is to the benefit of programs such as personal assistance. In this broader perspective, the alternative would be a far more fragmented and probably less cost effective system. Another important task is to study the factors contributing to a balance between independence and dependency among those needing extensive help due to their disabilities. All together, this calls for more research that could enlighten the implications of personal assistance for individuals, their assistants and for their families.

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