

Ten years with personal assistance



A report from the Knowledge Project

A presentation of two field surveys of people entitled to assistance.
The first survey was in 1995, the second in 2005.

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This is the third report from the Knowledge Project. The project is financed by the Swedish Inheritance Fund, and is being conducted by the JAG Association. The purpose is to contribute to developing the assistance reform for people with multiple extensive functional impairments, of which one is intellectual impairment. The project is also described on the JAG Association's website: www.jag.se

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On the cover: Kasper Hult, Daniel Härd, Matilda Berglund, Patrik Haase, Ronny Larsson and Emma Creutz. These people did not take part in the interviews.

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The first report was entitled "The price of freedom of choice, self-determination and integrity," and the second "The effect of personal assistance on the self-determination of intellectually impaired individuals: A systematic survey of the literature on international research." Both reports can be ordered from the JAG Association.

Summary

In 1995 the JAG Association interviewed 66 people about their situation. They were all entitled to assistance and had chosen Brukarkooperativet JAG (the JAG User Cooperative) as their provider of personal assistance. Ten years later, the 55 people still alive were interviewed again. Of these, 51 still have personal assistance. The average life span of those who have died since 1995 was 27 years.

Among the adults interviewed, most had a “god man” (personal representative), usually one or both parents. Almost all those interviewed had considerable communications handicaps as well as intellectual disabilities.

That parents and other relatives can be personal assistants is sometimes assumed to mean that the relatives become financially dependent on the person with disabilities, and that young persons with disabilities therefore remain in the parental home as adults, and whose development is therefore hindered. In fact, the results of the investigation indicate the opposite:

- In 1993, 20 percent of people over the age of 18 were living in their own homes. By 2005, nearly 60 percent of those interviewed over the age of 18 were living in their own homes. In 2005, fewer parents were working as assistants than in 1995.
- Assistance therefore provides the chance of self-determination in everyday life. However, this imposes considerable demands on proper management.
- The need for short stays away has declined markedly by 2005, as many more are living in their own home.
- By and large, the employment of relatives, the relief service and the home-help service were not being used by those interviewed in 2005.
- The need for nursing care and the number of hospital visits has fallen in the last 10 years. The health of those interviewed is said to have improved.
- The chance of continuity in training has led to faster rehabilitation for people injured as adults.

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1. INTRODUCTION

The purpose of the Knowledge Project is to gather and disseminate experience about personal assistance for people with intellectual disabilities. The interviews that formed the basis for this report present unique material and are a very useful asset for understanding the assistance reform.

The report “Ten years with personal assistance” is based on two field surveys with people using assistance, conducted at an interval of ten years. The first interviews were conducted in 1995 with 66 people entitled to assistance. They had all chosen the JAG User Cooperative to provide their personal assistance. The interviews give a picture of their life situations in the years before and after the assistance reform. They are published here for the first time. In 2005–2006 follow-up interviews were conducted with the 55 people still alive.

1.1 The Assistance Reform, LSS and LASS

The handicap reform initiated in 1994 resulted in two new Acts of Parliament – the Act (1993:387) concerning Support and Service for Persons with Certain Functional Impairments (LSS), and the Assistance Benefit Act (1993:389) (LASS).

This new legislation established that even people with disabilities were entitled to have control over their own lives. The objective, according to LSS, is to “promote equality in living conditions and full participation in the life of the community. The activities concerned shall be based on respect for a private individual’s right to self-determination and integrity.”¹

The measures shall ensure that a private individual shall have good living conditions. The target group to which LSS is directed is split into three groups of people, namely:

“people

- 1/ with an intellectual disability, autism or a condition resembling autism
- 2/ a considerable and permanent intellectual impairment after brain damage as an adult caused by external force or physical illness, or

- 3/ who have other major and permanent physical or mental impairments which are clearly not due to normal ageing and which cause considerable difficulties in daily life, as a consequence of which they need extensive support and service.”²

LSS is a law of individual rights. This means that someone who is covered by the Act, and who meets the criteria for the specified measures, has the right to be granted the measures he or she wishes to have. A rejection decision under LSS can always be appealed before a County Administrative Board. LSS lists the reasons for the handicap reform and specifies what measures people have a right to.

LSS gives a right to ten defined measures: advice and support, personal assistance and assistance benefit, escort service, a personal contact, relief service in the home, short stay away from the home, short periods of supervision for schoolchildren over the age of 12 outside their own home, arrangements for living in a family home or in residential arrangements with special service for children and young people who need to live away from their parental home, residential arrangements with special service for adults or some other specially adapted residential arrangements for adults, and daily activities for people of working age who have no gainful employment and are not undergoing training. Under LSS, it is the municipalities who are responsible for the measures, apart from advice and support, for which the County Council is responsible.

The entitlement to personal assistance is the part of the handicap reform that has attracted the most attention, and is also perhaps the measure that has come closest to realising the intentions underlying the reform.

LASS regulates the entitlement to personal assistance benefit. The objectives and underlying approach in LSS also apply to LASS. Under LASS, the costs of personal assistance are divided between the municipality and the State, and the benefit is granted by the Swedish Social Insurance Agency.

¹ Government bill 1992/93: 159 p 44

² Section 1 and 7 of the Act (1993:387) concerning Support and Service for Persons with Certain Functional Impairments

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Anyone who is not entitled to assistance benefit under LASS, but who nevertheless has a need for and entitlement to personal assistance can be granted personal assistance benefit under LSS (Section 9, subsection 2). This applies for example to people whose basic needs do not exceed 20 hours, or whose needs for personal assistance are not permanent. It is the municipalities who grant personal assistance under LSS and who bear the full cost.

The introduction of LSS and LASS demonstrate a clear change of perspective, manifesting a more humane approach and an environmentally related view of handicaps. The cornerstone of the legislation is that all people are of equal worth, and that people with disabilities should no longer be regarded as passive objects to be cared for by others, but rather as active people who can themselves ask for the help they feel they need. This help is provided at the initiative of the individual, and that individual should be given a decisive influence over how, where, when and by whom the personal assistance is given. Behind the assistance reform there is also a clear feminist perspective and a desire for fairness. The aim of the legislators was that the people, usually women, who previously had provided continuous daily service to people with disabilities in the form of unwaged work should now receive both wages and points towards a pension.³

1.2 The JAG Association and the JAG User Cooperative, 1992–95

The JAG Association (JAG in Swedish stands for Equality, Assistance and Community), was formed in 1992 by a small group of people with multiple major disabilities, including intellectual impairments. The association has both full members with disabilities and support members.

The JAG Association was set up as a reaction to the problems that people with multiple and extensive disabilities in combination with intellectual impairment had in trying to connect with the traditional handicap organisations. For example, Riksförbundet FUB (the Swedish National Association for Persons with Intellectual Disability), which organises parents, staff and people with disabilities, had a forum in which only

people with intellectual impairment were allowed to speak. That meant that those people who needed the help of a representative to express their views were excluded. In the associations of people with things like physical disabilities, vision or hearing impairment, it was generally thought that people with intellectual impairment were not suitable representatives for the group as a whole, and vice versa.

One of the JAG Association's first tasks was to campaign for the implementation of the assistance reform. That people with intellectual impairment were also covered by the new law is due to the work of JAG's chairman Magnus Andén and his predecessor Gerd Andén among others, who campaigned for this in Riksförbundet FUB.

The JAG Association brings together some of the most disabled people in Sweden. Geographically, members are spread all over the country. For many of them, the training courses and annual meetings of the JAG Association were the first contact with anyone else with equally severe and extensive disabilities.

In March 1994 the JAG Association set up a sub-association, the JAG User Cooperative, which like the JAG Association is a not-for-profit association. The JAG User Cooperative provides personal assistance for JAG Association members who want it. In the early years, just under 100 of the Association's 160 or so members chose to arrange their personal assistance under the Cooperative's management. During 1995 the membership of the JAG User Cooperative rose to 155.

1.3 Self-determination according to the JAG model

The JAG Association has a strong ideological basis – that everyone is of equal worth. Another attitude that permeates the organisation is the conviction that everyone has both the will and the capacity to exercise self-determination, provided they have access to the right communications aids and receive a response from those around them.

As part of the international Independent Living movement, a civil rights movement with its roots in the 1960s USA, members' self-determination is very important to JAG. In order to enable full members to achieve self-determination and to participate, a model has been designed:

³Inger Claesson Wästberg, 2004

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- Those who need help to make their case receive it from their legal representative (parent/person having custody for minors, or a personal representative for adults).
- The board of the JAG Association consists of full members, and only full members are entitled to vote at the Annual General Meeting. In the JAG User Cooperative, because of the responsibility placed on individual board members, the board consists of legal representatives (legal guardian or personal representative) for some members of the Cooperative.
- JAG’s full members cannot carry out all the tasks in the office, but there is a daily activity, the “JAG centre”, for some members of the Cooperative. They participate on their own terms, particularly in the policy and opinion-forming activities. JAG centre participants’ involvement in study visits, training courses and conferences is highly significant.
- Self-determination in assistance is achieved by each member of the cooperative appointing a “service guarantor” for support in managing the work and guiding the assistants. (In accepted usage the word closest in mind to service guarantor is *deputy supervisor*. We will in the following use the word service guarantor.) The service guarantor is often a close relative, though over the years it has become more usual for the job to be given to one of the assistants. The job of being a service guarantor may usefully be split between two people.

1.4 Purpose

The purpose of the Knowledge Project is to gather and disseminate experience about personal assistance for people with intellectual disabilities. The 66 interviews dating from 1995 constitute unique material and an important resource in understanding how assistance then worked in practice, as well as making it possible to look back on personal assistance 10 years ago. The new interviews are a valuable addition for describing the situation today for these pioneers of personal assistance in Sweden.

The reason why the JAG Association conducted the first interviews in 1995 was because the assistance re-

form was threatened by cost savings and cutbacks. By documenting what the entitlement to personal assistance meant for its members, the JAG Association hoped to be able to present evidence and information that would prevent ill-considered proposals for cost savings. JAG also wanted to see whether the members had gained better opportunities for a life like other people – one of the objectives of the assistance reform. However the material was never published.

1.5 Selection and methodology

The selection was based on the 100 or so people who in the beginning of 1995 arranged their personal assistance through the JAG User Cooperative. The ambition was to interview all the members of the Cooperative, but because of the large workload at the JAG office, only 66 interviews could be conducted at that time.

1.5.1 Interview round 1

In 1995, which was one year after the introduction of the assistance reform, 66 people were interviewed, both children and adults, about life before and after the reform. The interviews were conducted mostly by telephone, following a questionnaire (see appendix 1). The interviewing was done by Kerstin Ingren and Ulf Nilsson, advises in the JAG office. These initial interviews will from now on be referred to as interview round 1.

The questions were mainly answered by the interviewees’ representatives, namely parents or people having custody of members below the age of 18, and personal representatives for those over 18.

In the investigation, the life situations of the interviewees and their relatives in 1993 and 1995 were compared. The questions covered topics such as what needs for help and support the interviewee had before and after the reform, the quality of life, the opportunities for leisure activities, how much work was done by relatives, and the family’s financial situation.

One of the interviewees had no need for support in 1993. He was injured in 1994, at the age of 17.

1.5.2 Interview round 2

The follow-up interviews were done between May 2005 and March 2006 by project members Carina Ingren and Kerstin Sellin. One interview was done by Ulf Nilsson.

The questionnaire (see appendix 2) had been sent out before the interview so that the interviewee/representative could go through the questions in advance. In order

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to give the interviewees a real opportunity to participate, most of the interviews were done in the interviewee's home. Some interviews were done by telephone, by letter, at the home of the personal representative, or at the JAG office in Stockholm. Seven people had no personal representative. Of these, four answered the questions themselves, two answered the questions with the help of a parent, and in one case the parent answered the questions after agreeing that the answers would be sent to the interviewee for approval.

One of the interviewees had had a trustee for some years. But contact could not be made with the trustee who was at the time in hospital. Instead, there was a conversation with the previous personal representative.

Interview round 2 was 16 percent smaller, because 11 people had died. The average life span among those who had died was 27 years.

These follow-up interviews will from now on be referred to as interview round 2.

All details in the report referring to the time after 1995 are based on interview round 2 with only 55 people.

1.5.3 Description of the interviewees

In 1995 the average age of the interviewees was 23. The youngest was four and the oldest was 50 (see figure 1).

There were 39 men and 27 women. Geographically, the participants were distributed as shown below:

(Swedish counties)

Dalarna	9
Gotland	1
Kalmar	1
Norrbottn	6
Skåne	3
Stockholm	31
Södermanland	1
Uppsala	6
Västernorrland	1
Västmanland	3
Västra Götaland	1
Östergötland	3

Approx 70 percent of those interviewed had been born with their disabilities. The others had acquired their disabilities through illness or accidents later in life.

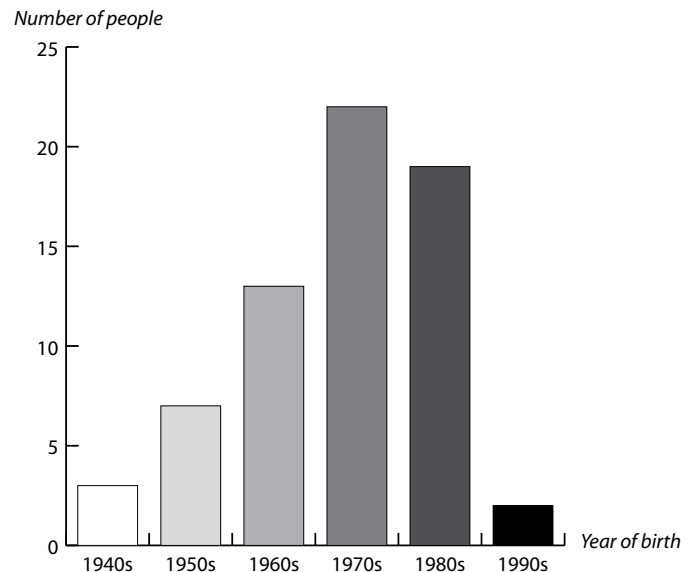


Figure 1. Interviewees' year of birth

The interviewees differed in some ways from the typical assistance user in 1995. Firstly, they had been granted significantly more hours of assistance per week than the average. In 1995 the interviewees had been granted on average 105 hours per week, compared to 67 hours per week among all assistance users. Actively choosing a provider of personal assistance was also somewhat unusual. Fewer than a third of all those entitled to assistance arranged an assistant other than the municipality that year.⁴

Many of the interviewees had experience of personal assistance in some form before the reform. This confirms the picture that it is a question of people with a considerable need of support, combined with a need for individually adapted measures.

In 2005, 51 of the remaining 55 interviewees were receiving personal assistance. Most of them need 24-hour assistance. 49 are still members of the JAG User Cooperative. Two have changed their provider of personal assistance. One is using the municipality, and the other a private company.

Three people have moved to group accommodation. One of these continues to have personal assistance for daily activities, with the municipality as the provider of personal assistance. One person has moved to a school boarding house.

⁴The Swedish Social Insurance Agency's statistics on the Internet, is-i 2004:2, appendix 1

2. SELF-DETERMINATION AND PARTICIPATION

Many of the interviewees need help to understand how things are interconnected, and the consequences of different decisions. In order to provide proper support for decisions, a personal representative must be able to communicate with the disabled person (the “user”), and have a good understanding of that person’s disabilities.

In the survey of the literature *The effect of personal assistance of the self-determination of intellectually impaired individuals: a systematic survey of the literature on international research* (Mälardalens Högskola, 2006), Jenny Wilder notes that there is a lack of studies about how personal assistance affects the opportunities for self-determination for people with intellectual disabilities. On the other hand, there are several investigations into how self-determination is affected by assistance for individuals with only physical disabilities. These studies demonstrate that self-determination benefits from personal assistance:

“The studies of the effects of personal assistance have focused on the target group of individuals with physical disabilities. These individuals have experienced greater control over their own lives, greater satisfaction with the personal assistance they received, and that they were in better health when they received their assistance through consumer-managed PAS [personal assistance]. They had significantly greater empowerment than individuals who received their assistance from a company-managed PAS. Empowerment is a synonym for self-determination (Wehmeyer, 1998). The studies selected for the in-depth overview studied various dimensions of self-determination, such as control over their own lives in the selection of assistants, the selection of how they should work and when, as well as in the choice of their own lifestyle. Satisfaction with personal assistance and the quality of life are also dimensions of self-determination, and it is through these variables that the consequences of self-determination become evident.”

Jenny Wilder points out in her report that it is a fallacy to suppose that people with intellectual impairment cannot exercise self-determination:

“Sometimes the argument is put forward that individuals with intellectual impairment cannot

show or have self-determination. This controversy is found both nationally and internationally (Wehmeyer, 1998). It is a fallacy based on confusing the notion of functioning independently with the right to self-determination (Wehmeyer, 1998). The number and type of capabilities influence the control that an individual has of his or her life – but so do circumstances affecting self-determination in the environment, as well as the individual’s experience. Research that has studied the interplay between children with intellectual and physical disabilities and their parents demonstrate how parents, by leading and updating the interplay to encourage the child’s initiative and responses, can promote optimal shared interplay (Wilder, accepted). It shows that small children can achieve a measure of self-determination in interplay – despite significant disabilities. It also shows that parental attitudes can provide support for self-determination by children. Individuals with intellectual and/or physical disabilities can show preferences and a wish for control, and this – in a supportive environment – enables them to achieve a high degree of self-determination and thus a greater quality of life (Wehmeyer, 1998; Wehmeyer & Schwartz, 1998; Lachapelle et al., 2005). If individuals with disabilities themselves cannot express their wishes in a way that is easily read, it is important that relatives, friends or close personnel are used as a communications channel (McCollum & Hemmeter, 1997).”

Jenny Wilder also discusses why there are so few studies in which people with intellectual impairment take part:

“Another aspect that is evident in the research in this subject area is that people are tied to certain research principles. There are two reasons why, for example, people have not included individuals

with intellectual impairment. One reason is purely methodological, and has to do with how data has been collected through self-assessed surveys by post or telephone. The researchers have argued for excluding individuals with communications problems or cognitive impairment. This view comes from the fact that the world of research has more confidence in its own assessments than in assessments made with the help of other people such as staff. One should be careful about suggesting that a person who knows the disabled person well might not be equally credible. There has been research investigating whether there were any differences between self-assessments and assessments made with the help of assistants – and no significant differences were found (see for example Stancliffe, 1999). The other reason is that the world of research has less faith in instruments that have been modified to suit individuals with cognitive impairment. Fundamentally, this is to do with the fallacious attitude that self-determination is simply not possible for individuals with intellectual impairment (Wehmeyer, 1998).”

2.1 Legal guardianship

In Sweden a person who, by reason of illness, reduced autonomy or suchlike, needs assistance in order to protect his or her rights, to manage his or her own property, or to look after himself or herself, has the right to a personal representative. A personal representative is appointed by a court of law to meet the needs of individual, and the representation can be limited to one or two of the above-mentioned areas. A personal representative has an advisory function. The principal retains his or her own full legal competence, and the personal representative may not in principle take any action contrary to the disabled person’s wishes.

Of the interviewees aged over 18, the overwhelming majority had a personal representative. The job of the personal representative involves far more than simply making decisions on behalf of the disabled person. For example, many of the interviewees need to have complex circumstances and abstract concepts explained to them, and support in understanding the consequences of a particular decision. A personal representative must be communicating well with the disabled person, and

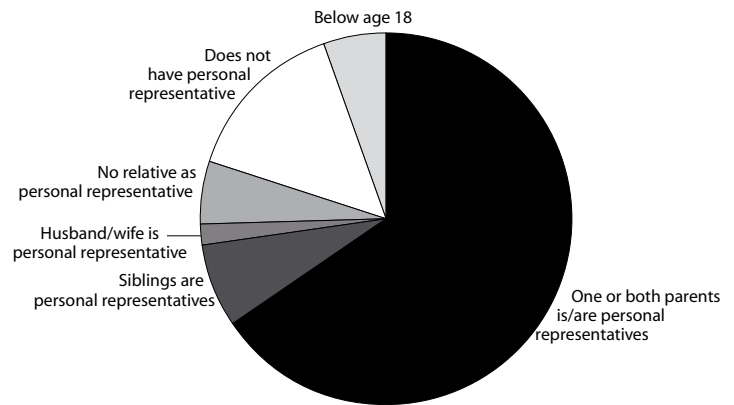


Figure 2. Interviewees' relationships to their personal representative 2005

have an understanding of the functional impairment so as not to underestimate his or her capacity for self-determination.

A well-functioning guardianship is often a precondition for properly functioning personal assistance. The personal representative is responsible, among other things, for applying for a sufficient number of hours and hourly amounts, and to engage a suitable provider of personal assistance. In the JAG User Cooperative, the personal representative may be a service guarantor, in other words responsible for staffing and supervising the assistants. If the personal representative does not wish to take on this task, then he or she must, in consultation with the JAG User Cooperative, assist the disabled person to find a suitable person for this task.

Throughout, the interviewees' personal representatives showed great commitment and a very serious approach to their assignment.

In order to manage their lives in practice, every day and in every situation, it is often important that the person appointed as the personal representative should be someone well known to the disabled and who is literally close at hand. The interplay between the interviewees and their personal representatives was in most cases based on a very close relationship.

In 2005, just over two-thirds of those interviewed were represented by one or both parents (see figure 2).

Olof was born in the mid-1980s. "Olof communicates mainly by signs and photographs, mainly digital pictures. He also has a board with personal pictures that stand

for I want, am happy, sad, want different meals etc. He answers clearly by saying “mmmm” or by pointing. When he means No, he crosses his arms. I support and encourage him to make his own decisions by giving him choices in everyday situations,” says his mother who is also his personal representative.

Those who are close to a disabled person often have a far deeper understanding of this person than anyone else. People who subsequently come into the life of this person naturally do not have the same knowledge about the his or her experiences and choices in life. For the individual, it is important that the knowledge built up by close people is utilised, and that appropriate information is passed on to the right person.

Helge was born in the mid-1940s. His personal representative is not a relative, and neither is his service guarantor. Before Helge’s mother passed away, she specified how the service guarantor and the personal representative should meet her son’s wishes and needs. Particularly for recruitment of assistants, they lean towards his mother’s instructions that they should be a mixture of both “mummies and guys”.

Tomas was born at the end of the 1970s. “I knew Tomas before his accident, so for me it is important that he goes on living a normal life just like everyone else,” says his mother, also his personal representative.

Many personal representatives who are also relatives are worried about the future. Who is going to make sure that their children’s rights are protected when they are no longer around?

Bo was born in the mid-1970s and has lived for some years in group accommodation. Bo’s mother, also his personal representative, feels that as he has no other relatives or people close to him, the obvious thing would be for someone else in his group accommodation to become his personal representative when the day comes that the parents can no longer do the job. “We are terrified about what might happen in the future, when we are no longer around to help Bo,” she says.

When one of two married people or partners, with a long shared life behind them, need additional support, the natural thing is that the husband or wife is appointed to be the personal representative.

Sven was born in the early 1950s. His wife was appointed as his personal representative when he was injured in his 40s. “Sometimes Sven asks me to decide, and sometimes it is really important for him to make his own decision, for example what to eat for dinner, or where – if they are going out – or what clothes to wear. Sometimes he wants to wear something particular, but he has no idea of the changing seasons. I try to let Sven make decisions as much as possible, but sometimes we row, for example about his smoking.” she says. Sven needs increased benefits, and this has been granted, despite a degree of resistance from the Social Insurance Agency, because he does not always make use of all the money. “It depends on his health. Sometimes he is ill, and sometimes he just doesn’t want to do anything. You can’t force a grown person to do something he doesn’t want to,” says his wife.

Seven percent of the interviewees have a sibling as their personal representative.

Eva was born at the end of the 1950s and lives in her own flat. She has two sisters. One of them is the personal representative and works as the personal assistant for eight hours a week. The other sister is the service guarantor and works full-time as Eva’s personal assistant. Eva shows by her body language and gestures that she is proud of being able to manage her own life. “Eva shows by clear gestures what she wants. It is important for Eva to make it clear that she is the one who decides,” says her personal representative.

Five percent of the interviewees lack a family connection with their personal representative.

Ali was born in the early 1980s. He is not related to his personal representative, but has known her for a long time. “We have known each other since Ali was five. I talk to him, and if he agrees he repeats what I just said, otherwise he just ignores it. I say: “Hello, Ali” and he repeats “Hello, Ali” as a greeting to me. Once you know Ali, you un-

derstand how he functions. When he wants to be left alone, he shuts the door. If he wants company, he leaves it open,” she says. From the personal representative’s answers, it is clear that all decisions are made in consultation with Ali’s parents. She sees her main task as making sure that Ali is okay and feels secure. During the day, Ali gets support and service from the staff at the daily activities. At other times his parents and siblings work as assistants. “As it is just the family, I think it is working well. But if we had to train up an outside assistant, that would also work well,” feels the personal representative. The personal representative finds that parents regard it as self-evident to assist Ali as long as they can. “The mother sees it as her duty, and it is a conscious choice. But it is certainly easier now that she gets paid for the work she does,” says the personal representative, adding that the parents had previously helped Ali at all times outside school hours without remuneration.

There are several examples in the material showing that the personal representative must be prepared to stand up and fight for the disabled person.

Örjan was born in the mid-1970s. He and his mother, who is also his personal representative, had a meeting some time ago with the staff at the daily activities. “Örjan talks of course, though perhaps it’s not always relevant,” explains his mother, and continues: “The officials from the municipality asked such leading questions that they got Örjan to say exactly what they wanted. So I had to step in and say that it wasn’t so. Örjan didn’t just want to sit and eat and go for walks during working hours.” About her roles as personal representative, service guarantor and personal assistant to her son, this is what she has to say: “You don’t have a choice, that’s how things are and it works. I learnt early on that I had to fight for Örjan. Ideally I just want to be his mother.”

David was born at the end of the 1970s. “Group accommodation carries responsibilities, but I consider that as a representative, so do I,” says his mother. “If I notice that David is not getting enough stimulation, I make a fuss and make sure he gets more activities. It is very challenging. I need to play an active part in David’s life. I make a fuss if they bring in staff that David does not like. At this moment, things are working well, but I will soon need to make a fuss again. What David enjoys most is swimming – using

his whole body. That’s happiness, and when I see that he is enjoying it I am prepared to make lots of fuss so they let him swim.”

Often it is the personal representative’s commitment that is decisive in various situations.

Roger was born at the end of the 1950s. His mother describes what it was like when her son applied for personal assistance in 1994: “I sat there and was cross-examined about Roger’s needs by ten men, but I was a stubborn mother and he got approval. That was a huge relief.”

Bengt, born in the middle of the 1940s, recounts how his mother, now departed, had to fight for his rights. “It’s hard to remember now, but I think I had home help – someone came a few times every day. It didn’t work well and Mum had to fight with the municipality to get more help.” About being represented by someone else, he has this to say: “I accepted that Mum sometimes argued my case, but not always. But it is much harder when an assistant does it.” Bengt currently has no personal representative, but he has given power of attorney to someone he trusts to represent him in specific matters. “Since Annie has had power of attorney, I feel much better informed. She is great, and I think she should go on having power of attorney, and that I don’t need a personal representative. Annie functions as a personal representative, but does not want it formalised. At the moment, personal assistance is working well, I don’t want a personal representative, just someone who has power of attorney and respects me. It’s nice that no one else takes over my decisions.”

2.2 Communication

Almost all the interviewees have considerable communications handicaps. It is not always easy for parents or the personal representative to explain how he or she communicates with the disabled person. In conversations during interview round 2, there were some specific examples showing that it was not a question of any sixth sense or mind-reading – as people might believe, because the interplay is so practised, and the interviewees’ signals and reactions are sometimes hard to grasp for outsiders.

“It is hard to offer things to Rebecka and see whether she likes them. Sometimes you have to offer the same thing several times. She does eventually show whether she likes it or not. She becomes cheerful, laughs, scratches her head and stretches out her legs. When she’s feeling well, she wipes her hand across her mouth and nose. We have had a communications box, it’s a box where we put things like a swimming suit, a cap or a spoon. Things we show Rebecka before an activity, so she knows what is going to happen,” explained her personal representative. “When we are at the cottage, Rebecka’s dad carries her from the cottage down to the boat. She gets very excited, so she does show clearly what she enjoys,” she continues.

Some of the interviewees who lack normal speech make use of various technical communications aids. It is very common to use “private” words, or perhaps people have agreed with those closest to them about the meaning of various gestures and movements.

Hanna was born at the end of the 1970s. Her mother describes how they communicate: “Hanna can say Yes by looking at her right hand, and No by looking at her left hand. She can also make various sounds meaning Yes or No. She uses about 400 Bliss symbols, mostly the ones that describe feelings. Mimicry is also important in communications. Hanna looks and guides us with her gaze. At home, Hanna mostly uses Bliss just as extra support when needed, but in her daily activities she always has the Bliss chart in front of her.”

Filippa was born in the mid-1970s. She pushes her wheelchair around herself, and can clearly show what she wants, for example by fetching a spoon when she wants to eat. “She stretches out her hand when she is finished on the toilet, and pushes you away if she was to stay longer. We don’t have any special system. It all happens spontaneously, and always has to be interpreted,” says her mother who is also her personal representative. “Filippa cannot confirm with a “Yes” or “No”, but indicates clearly if she is dissatisfied or insecure in a situation by for example biting herself in the arm. That means she is not feeling okay, and something needs to be changed,” she says.

The personal assistant is an important means of communicating, helping with interpreting both to understand and be understood.

Olof was born in the mid-1980s. “Olof cannot let us know himself when something is not right,” says his mother. “There is also a risk that he believes that’s how things ought to be, even when something is not right. He is very dependent on having a good assistant along, for example at school who can be his means of communicating, and can tell us at home what’s happened at school,” she says.

Lars was born in the early 1980s. “Lars has no speech, he has his own gestures. He points, pulls and pushes me in the direction he wants. He can also shake his head, but this does not always mean No. You have to read his body language, his moods and the tension in his body. He may also refuse to come – above all you must know Lars. If he is not happy during the day, the personal assistant must understand that it is part of his work to report this to me as the representative. Communications are the most important thing. Without that, you are just a care package that is carried around. Imagine what it must be like to have assistance in every situation in daily life from people who think they know but don’t listen,” says Lars’ mother.

2.3 Self-determination with decision support

Our starting-point is that everyone can exercise self-determination, for example by showing approval or disapproval in any situation. This is also confirmed in the interviews. Achieving self-determination of this requires that the surroundings can interpret and draw the right conclusions from your way of expressing things, and no less important, to respect your decisions.

Björn was born in the mid-1950s. He needs to try out various things and then show what he thinks. By actions and body language he shows whether he accepts a suggestion or offer, or what else he wants. “When he moved into his own flat, we did not discuss things in advance. He just moved into the flat to try out living there for a few months until I was sure he was happy and enjoying it. Only then did he give up his flat in the group accommodation. As his personal representative, I sometimes make choices on Björn’s behalf. He tries things out and then shows what he thinks. It is then up to me to interpret his actions correctly.

Sometimes the results are evident only after a while, but other things happen at once,” explains his personal representative and mother.

Sophie was born at the end of the 1970s. She has a very close relationship with her mother who is also her personal representative. “You have to know each other very well, that is a precondition for being able to interpret Sophie’s wishes. This is based on years of experience. Perhaps Sophie doesn’t want to get up in the morning, but if I don’t help her to get out of bed, she gets very hungry, and angry that she hasn’t had any breakfast. Sophie cannot foresee the consequences of her decisions, so I have to help her with that. It can be hard to tell whether it is just too much effort to get up, or whether she is sick and really needs to rest. But if she really means it, she will keep on protesting. If I make the wrong decision, Sophie lets me know by making herself even more clear. Knowing each other is essential for being able to help to make the right decision,” notes her mother.

Ingemar was born at the end of the 1950s. “Ingemar says little himself, says more if he is feeling well. If he needs something, he points to a letter board. Otherwise we try to interpret his facial expressions and watch his hand mimicry,” says his father who is also Ingemar’s personal representative. He helps Ingemar to make decisions by asking questions. “If he wants something new, we try it out. Once we went to a wrestling match because he wanted to, but

once there he changed his mind, so we just had to come home again. It is important to be able to make last-minute changes.”

Lotta wants to join in and make decisions, she has clear goals for herself and knows what she wants. Her mother is not officially her personal representative, but has applied. “In the beginning, Lotta had no speech. We communicated by sign language. Though today we talk as normal. I have to think carefully how to express myself. What’s important is not to talk too childishly, because that humiliates Lotta. She always points out that she is now grown up. I can tell whether she has understood by eye contact, body language, tone of voice and behaviour. She may often answer “Yes, yes”, even when she hasn’t understood. It’s very important to notice this. Having been together for years helps me to understand her better. It also helps to have an understanding of her disability. All the nuances need to be learnt. To communicate with each other it is important to be able to take a step back if I see that Lotta doesn’t understand. To express it more specifically and help her compare what we are talking about with something else can help. One day she may think this and another day that. It is important for me to work out and be aware of why she has changed her mind, and to talk about it. Everything needs to take time and I need to be patient and answer all Lotta’s questions so that her decisions are her own, and that they are sound and safe decisions,” explains her mother.

3. ACCOMMODATION AND SERVICE

In 1993, over 80 percent of the interviewees lived with their parents. They received a large part of their support from their parents, who did not receive any financial remuneration matching their efforts. By 2005, nearly 60 percent of the adult interviewees with personal assistance had been able to move into their own accommodation.

3.1 Forms of housing

Historically, the support offered to people with extensive disabilities started with the choice of the form of housing – for example nursing homes, group accommodation, accommodation service and home help service. You could say that the “help was within the walls.” The same applies today for all measures apart from personal assistance.

3.1.1 Shared households with parents

In 1993, over 80 percent of the interviewees lived in shared households with their parents. They received a large part of their support from the parents, but were also offered other things, for example short stay visits or family homes. A large part of their support was given by the parents, who did not receive any financial remuneration matching their efforts. Because the parents gave the support without remuneration, there was no possibility of exchange, and that is why one can say that their help was “within the walls”.

By 2005, the proportion of people living with their parents had fallen to barely 40 percent. All have personal assistance as their main measure.

3.1.2 Own home

In 1993, barely 20 percent of the interviewees over the age of 18 were living in their own homes. Of these, three people were married or had partners. Some had a degree of personal assistance even before the reform, while others received support and service through the home help service and from relatives, partly as relative carers and partly without remuneration.

By 2005, nearly 60 percent of those interviewed over the age of 18 and receiving personal assistance were living in their own homes.

Several of the interviewees reported that the move into their own homes was a long process. There are many different factors that must all come together.

Rebecka was born in the early 1970s. Her personal representative says: “Rebecka’s decision to move into her own flat is something we did together as a family. It was a big decision, but as Rebecka was now 30, we thought it was the right time. Rebecka also had three assistants who came back after time off, so she didn’t need to employ any new assistants.”

Moving into your own home requires adequate financial circumstances, and access to adapted or otherwise suitable homes in the right area.

Anton was born at the end of the 1970s, and lives with his mother in a large flat in an area where he is happy. He would like to have his own home. Most of all he would like to stay where he is, and not have to move to somewhere new and strange. “Where I live, there are nice neighbours above and below my flat, they understand me. But financially, there is no chance of living alone in the flat if my

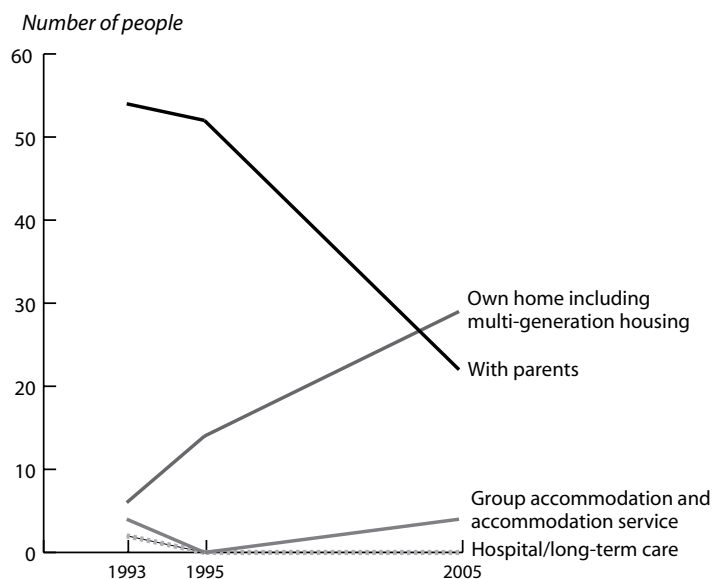


Figure 3. Changes in the interviewees’ forms of living 1993 – 2005. Reduction in 2005: 11 people deceased.

mother moves out,” he explains with help from his mother who is also his personal representative.

3.1.3 Multi-generation housing

A common stage on the way to an own home is various forms of multi-generation housing. By rebuilding or converting the parental home, several of the interviewees now have a private section. Multi-generation housing is an “in-between form”, not entirely a home of your own, but with the extra security of living near the parents. Multi-generation housing is in many cases also a financially advantageous form of living.

Rasmus was born in the mid-1980s. He lives in his own home, backing onto his parents. “Multi-generation housing is a brilliant solution which I think will work well long-term,” says his mother and personal representative. Since becoming an adult, Rasmus has employed several outside assistants. Both Rasmus’s parents also work as assistants if needed. The previously worked full-time as assistants, but now have other jobs outside the home, and have started to scale down their work as assistants. “As parents, we want to have our own life, and not just be Rasmus’s assistants – even though we will always be here for him,” says his mother.

Pontus was born in the early 1970s. He lives in his own flat on the ground floor, with a connection to his parents’ flat alongside. In the house there is access to a common room with a billiards table and darts, pub evenings and suchlike. With his parents, who both work as personal assistants, Pontus has opportunities for spontaneous trips by car or boat during free time. “Pontus decides, he loves being outside even if it is raining,” says his father who is also his personal representative.

After a severe injury and a long hospital stay, Benny, born in the early 1970s, moved back to his parents in 1993. “The municipality wanted me to move into group accommodation then being rebuilt. Personally, I wanted to convert the garage in my parents’ house into my own flat. The municipality didn’t like the idea, and wanted to adapt my parents’ whole house. It was a hard struggle for the whole family,” says Benny. He finally got help to furnish suitably adapted housing in his parents’ villa, and had a mix of municipal personal assistance and help from the home

help service’s night patrol. The home help service did not function well – they woke up the whole household when they arrived. Benny is now at school in another location, and lives right next to the school during term time. He gets help from personal assistants both in the school and outside school hours. Holidays are spent in his flat in his parents’ house. When he leaves school, his parents think that he will want to move into his own home, and perhaps even get other service guarantors. As over the years Benny has become more and more actively involved in assistance, his parents believe that the role of service guarantor can now be more easily filled by people other than the parents.

3.1.4. Group accommodation and accommodation service

In 1993, two of the interviewees lived in group accommodation, and two lived in flats with accommodation service. By 2005, two of these had died and two lived in their own flats.

Robert was born in the early 1960s. From the ages of 21 to 34, Robert lived in group accommodation. For him, it was liberating when he got personal assistance in 1994 and was able to move from group accommodation into his own flat. For Robert, the most important thing is that he can now decide for himself. “Previously, it was the staff who made the decisions. I didn’t really get on with them. The system was wrong.” Robert gives an example: “The staff used to take my cassette tapes down to the cellar because it was too much work to tidy my room. I had no privacy and felt uncomfortable. It just doesn’t compare,” he says. “I couldn’t have managed without personal assistance. Other people used to decide so much for me, now it is nice to make my own decisions.” Robert now has assistance 84 hours per week. The assistant usually begins his shift at 11 a.m. and works until 9 in the evening. At other times Robert has a security alarm connected to the home help service. He usually stays in bed in the morning, listening to the radio or watching TV. He eats the breakfast that the assistant has put out the previous evening. Previously, Robert had daily activities, but he stopped that at his own request a couple of years ago. “That was the best thing I have done“, he says. “Now I am at home instead. It suits me better, and I don’t have to get up at 6 o’clock in the morning.”

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Four other interviewees have moved into group accommodation or a school boarding house, and get most of their support there:

Bo was born in the mid-1970s. His parents could not see any conceivable personal assistance solution. His mother, also Bo's personal representative, explains: "My husband said that if we are to survive, Bo needs to move away from home. You have looked after Bo for 28 years. Now it is someone else's turn." In 1993 Bo was living at home with his parents. His mother had a full-time job as a personal assistant, but in practice helped her son round-the-clock, apart from the time he spent at the day centre. Bo had another personal assistant with him for the daily activities, but at other times only his mother helped. The parents did not want any outsiders in their home. When suitable group accommodation was built nearby, they applied for a place for their son. "I try to persuade myself that he is okay" says his mother. She is very worried about her son's situation. The question of Bo moving into his own flat with personal assistance was discussed, but didn't happen because of the parents' concern that his mother would have to step in and work as a personal assistant day and night.

Andrea was born in the mid-1960s. Following the change in legislation in 1996, she was granted only 20 hours of personal assistance per week, after previously being entitled to 40 hours. The situation was unsustainable. Even if Andrea had daily activities during the daytime, and stayed at short stay homes for 5–6 days a month, her mother felt exhausted. She worked half-time as an assistant and supported her daughter at other times. At the end of the 1990s the municipality decided that assistance would end, and offered group accommodation.

David was born at the end of the 1970s. His mother and personal representative says that her son's move to group accommodation felt inevitable. "It wasn't a real choice, we had problems finding staff and the future seemed insecure. Of course there have been many disappointments on the way. I had illusions that things would turn out better. It feels as if I have run into a brick wall" she explains.

3.1.5 Hospital/long-term care

Several of the interviewees have experience of long stays in hospital or long-term care.

Karl, born in the early 1960s, was seriously injured in his 30s. After a year in long-term care, he got a place at a rehabilitation centre. He was granted personal assistance by the municipality so he could go home to his partner and children at weekends. His partner and Karl's father also provided a great deal of support and service without remuneration. In 1994 Karl was given personal assistance for 210 hours per week, and moved into his own flat.

Pelle was injured in 1993. During his hospital stay, his relatives received compensation from the municipality if he was home for more than six hours. He stayed in hospital until 1995 when he was granted personal assistance for 126 hours per week. Since then he has lived in his own flat.

Sven was injured at the end of the 1980s. He was nearly 40. For the first five years after the accident, he lived at the hospital but went home almost every weekend. In 1993 he was given personal assistance for 90 hours a week by the municipality and was able to move back home. The municipality did not want to employ his wife as a personal assistant, but they did want her, despite having a full-time job, to work extra hours when there were no assistants available for her husband. In 1994 Sven switched to another provider of personal assistance. He was given additional hours, his wife was employed as personal assistant and also took on the job of being in charge of the assistants. After the accident, the couple moved to a new house. "We will go on living here in future. I will look after him as long as I live," says his wife.

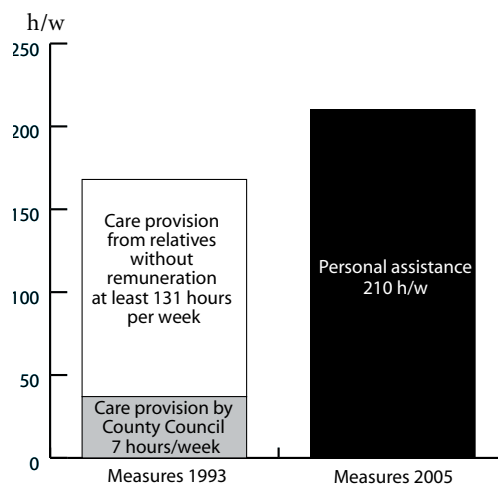


Figure 4. Roger and his care provision in 1993 and 2005

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After his serious injury, Roger stayed alternately in long-term care and in his own home. “Roger was in long-term care during the day while I was working. He was forgotten, as he couldn’t make himself heard” explained his mother. Then he moved home to his parents again, where the County Council offered home nursing care for 37 hours per week. The rest of the time he was looked after by his parents as needed. Following the assistance reform, Roger was given personal assistance for 210 hours per week, and was able to move into his own home (see figure 4).

Mikael was born in the early 1960s. After a severe injury as an adult and a long hospital stay, the County Council offered him a place in long-term care. But with the help of his parents, his partner and a good friend, Mikael was able to move into his own adapted home. His partner and friend were employed relatives for 100 and 50 percent respectively. He also received help for two hours a day from the home help service. In 1994 Mikael was given personal assistance for 188 hours per week. His partner worked as service guarantor and personal assistant up until his death.

3.2 Supplementary service forms

In 1993, the interviewees were granted the following care provisions:

- 33 people stayed regularly at short stay homes and/or with short families.
- 30 people were granted a particular form of personal assistance, 20–168 hours per week
- 21 were granted relief services
- 17 people had relatives employed, 20–60 hours per week
- 11 had home help services
- Four lived in group accommodation or accommodation services
- Two people were staying in hospital

Below we will look in more detail at some of the care provision that the interviewees were offered before the assistance reform.

3.2.1 Home help service and relief service

In 1993 one-third of the interviewees had relief service, on average six hours per week. Over 15 percent had home help service, on average 10 hours per week. In

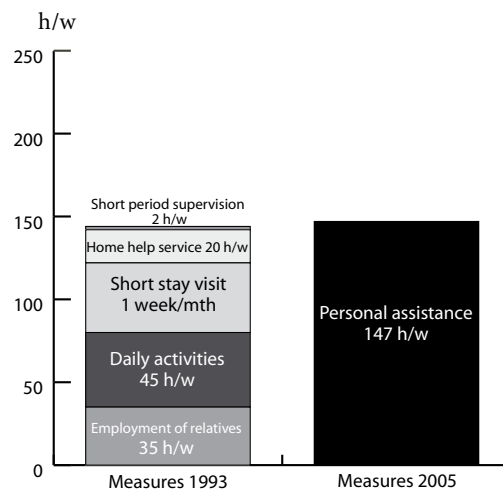


Figure 5. Andreas and his care provision in 1993 and 2005

2005 there was basically no relief service or home help service.

For some people, life became rather fragmented because of the variety of care provision being offered.

Andreas was born in the mid-1960s. Before the assistance reform, he had short period supervision, short stays away, daily activities and the home help service (see figure 5). Home help service domestic staff came two by two. “In the end, they had no one who wanted to work,” says his personal representative and mother. Over a period of three weeks, 18 different people came to Andreas, and that made him feel quite bad. That in turn meant that he developed behaviour that the home help staff regarded as aggressive. None of them knew him well enough to see the connection.

3.2.2 Short stay visits

The purpose of short stay homes or family homes is normally to provide some relief for the family members sharing the same home. Therefore obviously short stay and family home visits only take place for people who live in a household with other people, and this ceases if or when they move to their own home.

In 1993 nearly 60 percent of those who lived with their parents stayed in short stay homes or in short stay families on average 30 hours a week. In 1995 fewer people used short stays and/or family homes, but on the other hand, the average visit length had increased

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a little. In 2005 the use of short stay families and short stay homes has fallen substantially, both among young and old. About 10 percent stayed in short stay homes, and the average visit length has fallen to a little over 20 hours a week.

Many interviewees stated that it was difficult to use the short stay visit, because of the low quality of care on offer there.

Lena was born in the early 1980s. Her mother, also her personal representative, explains that Lena had a place at a short stay home at the start of the 1990s, but didn't want to be there. "Eating takes her an hour and a half, and at the short stay home there were only two staff for six children. She was always hungry when she came home. They just didn't have time to help her. There wasn't time either to use Bliss. Lena's brothers and sisters also wanted her back at home. They thought it was wrong to send away the child who had the hardest life," says her mother.

From 1995–99 Filippa, born in the mid-1970s, spent around 10 days a month in short stay homes. The rest of the time she was living in the parental home. But the short stays did not work well, says her mother, also her personal representative. This was the case even though in the last year Filippa was allowed to bring her personal assistants to the short stay home. "The staff couldn't see that we parents could also be a resource. They thought they knew best. There was a large staff group with up to 13 people who worked on a rolling timetable." The solution in Filippa's case was that she stopped going to the short stay home. Instead her parents would leave the house from time to time. In 1999 Filippa moved to her own flat. "It was only later that we understood how bad the short stays had actually been," says her mother.

Adam, born in the early 1970s, has also had bad experience of short stay homes, where he normally spent one week a month. "I have used a short stay homes, but they

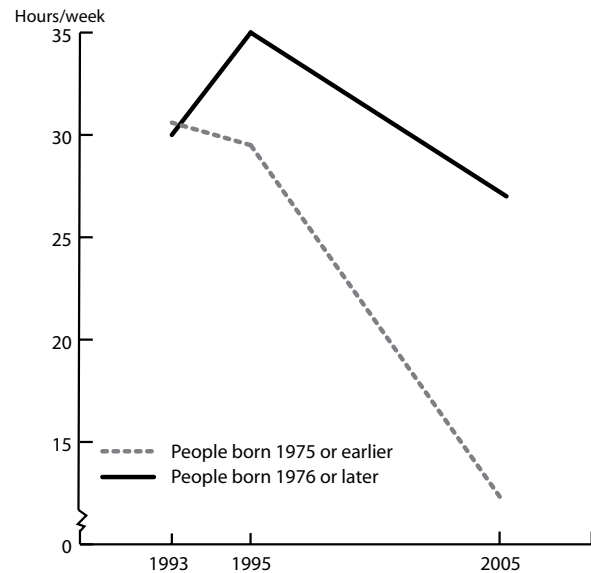


Figure 6. Short stay visits in average hours /week

haven't always been that good. I almost always slept badly when I was small, was exhausted when I came home, resulting in more and more vomiting for long periods," he explains through his mother who is also his personal representative.

Various kinds of summer camps, or extended stays at short stay homes during the summer, were quite usual before the assistance reform, particularly among the young. One in four of the interviewees born in 1974 or later stated that he/she has spent a number of weeks at summer camps in 1993.

Adam too spend four weeks of the summer at a short stay home for a so-called holiday. Even in 2005 he was spending some weeks of the summer at the short stay home, as the day centre closes for one month in the summer. We will return in chapter 5 to the problems of not being granted personal assistance for daily activities.

4. THE ROLE OF RELATIVES

Some of the parents of interviewees say that one benefit of the assistance reform is that they can give support and service to their children and at the same time have the security of paid employment. Others wish they could be less involved in assistance and “just be parents.”

4.1 Relatives’ livelihood/employment

One important question is how the interviewees and their families managed financially before the assistance reform.

In addition to an early pension for the interviewees aged over 16, it was also possible to obtain care allowances or disablement allowances, home nursing allowances, rent allowances etc. In many families one parent, typically the father, worked full-time away from the

home, while the other parent gave support and service to the child. Sometimes the parent who took the main responsibility for the child was able to work part time away from home while the child in school or in daily activities (see figure 7).

In 1993, fewer than half the interviewees’ female relatives were in employment. Around one fifth were not working. This group includes people on parental leave, those off sick or job-hunting. One fifth were employed

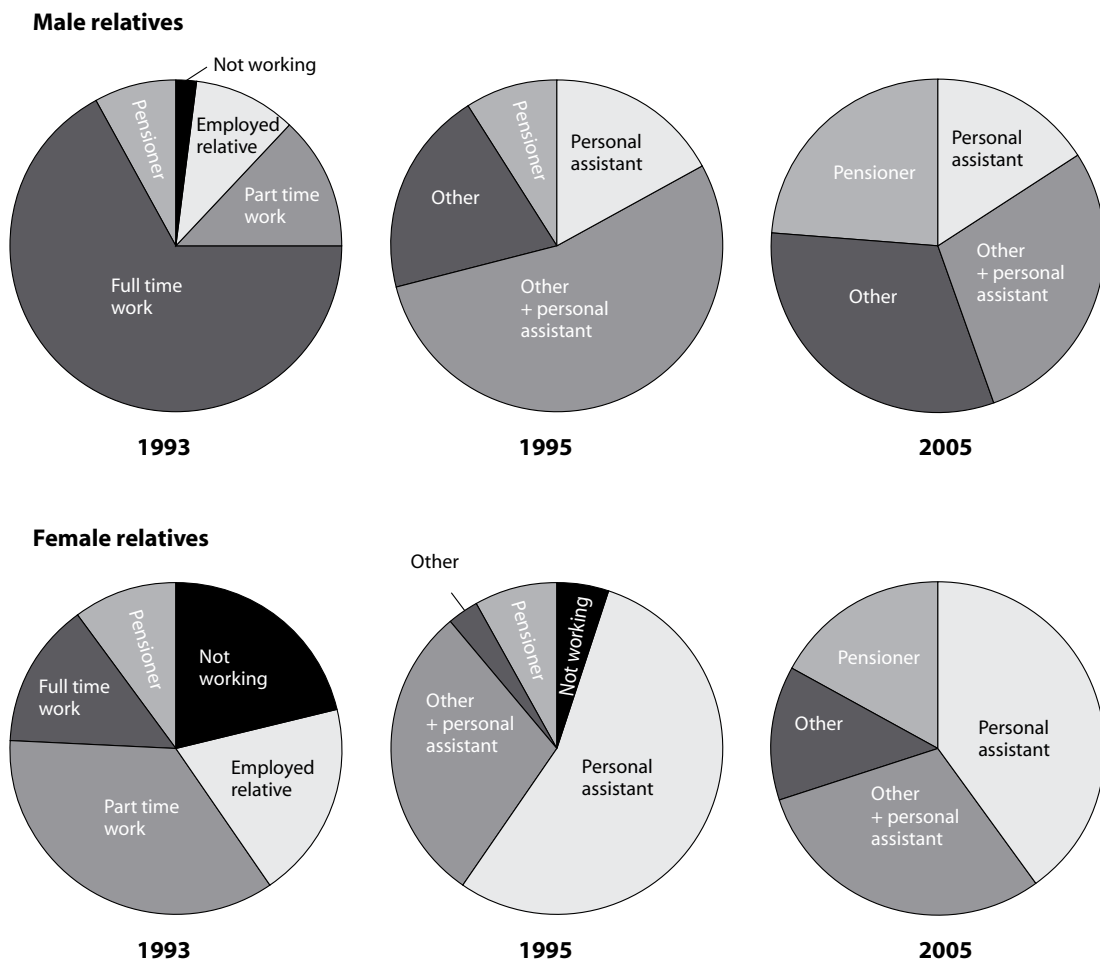


Figure 7. Main livelihood/employment among interviewees’ relatives. Only a husband/wife, partner or parent is included here as a relative. The group “Not working” includes people off sick, people on parental leave and those job-hunting. Included among pensioners are a number of people who if necessary work as personal assistants.

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relatives, usually with very unfavourable terms of employment, including unregulated hours of work. Following the assistance reform, the activity rate among these women increased to 94 percent (excluding pensioners).

In 1995, many of the interviewees' relatives, particularly men, had reduced their working hours away from home in order to combine work away from home with employment as a personal assistant, or to work only as a personal assistant.

The assistance reform – which had the express purpose of putting a price on the support and service provision normally carried out by women – seems therefore to have helped to make more visible the care provision from men.

By 2005 the number of parents, both men and women, who work mainly away from home, has again increased. We will return to this below.

4.2 From employed relatives to assistants

Prior to the assistance reform, it was common for the interviewees to have some form of personal assistance at school, while employed relatives provided support and service outside school hours. Following the assistance reform, the employment of relatives among people close to the interviewees ceased.

Lena was born in the early 1980s. In 1993 she had assistance at school for 20 hours a week. Her father was employed as a relative care provider for 30 hours a week, and her mother worked half time away from home. In 1995 Lena was granted 112 hours of assistance remuneration per week, and both parents were employed as personal assistants. In 2005 Lena was still living at home, with both parents working as assistants.

As shown in figure 7, the general opportunity that came with the assistance reform to employ relatives and other closely connected people as personal assistants seems to have met a very great need. In 1995 just over 60 percent of the interviewees had at least one relative or other close person employed. On average, relatives or other associates provided nearly 50 hours of assistance a week.

Ten years later the trend has reversed. A growing number of parents have reduced the time they work as personal assistants or have stopped working altogether. This cannot be explained purely by their increasing age. By 2005, the interviewees received assistance from rela-

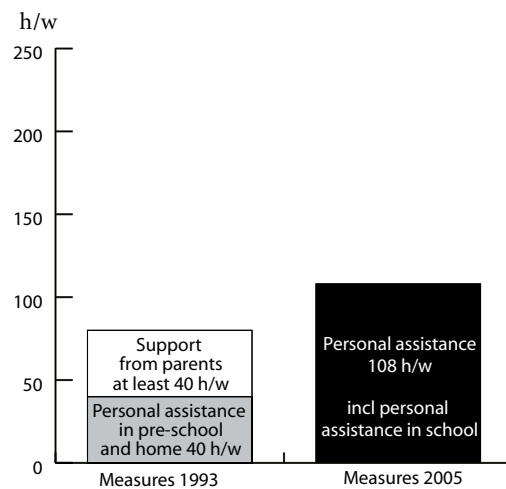


Figure 8. Olof and his care provision in 1993 and 2005

tives or other close associates for an average of 40 hours a week.

Olof was born in the mid-1980s. He lives at home and is still at school. "I have been working full-time as assistant and also been service guarantor since Olof changed his provider of personal assistance from the municipality to the JAG User Cooperative in 1994. He no longer believes that we parents function that well as assistants, and that we should try to work less and less. When Olof leaves home, I reckon that he will only have other people employed as timetabled assistants, but that I will continue to be his personal representative and service guarantor, at least for the next few years," says Olof's mother.

That the parents are working less as assistants fits in with the increasing familiarity with the form of support as such. People dare to recruit "outside" assistants.

Adam, born in the early 1970s, has moved to his own home backing onto his parents. His personal representative and mother says: "Adam would like to have us parents as assistants – but not too much. We worked a great deal in the beginning, but then brought in one assistant after the other, depending on how things worked out. Adam's father now works just a couple of hours a week when Adam goes riding and needs double assistance."

Once people start to think about moving to a home of their own – if not before – the question usually arises whether to start employing assistants who are not relatives.

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Anna, born in the mid-1970s, has been living in a flat a few miles from the parental homes for the last 10 years. Her mother, who is also her personal representative, says that it was a gradual development, as Anna started recruiting personal assistance from outside the family circle. Anna has had personal assistance at nursery school since she was three. In the early days, the family provided all the support in the home, but as Anna grew older, more assistants were employed. "I have always helped Anna, regardless of employment," says her mother. "When Anna joined JAG, I started working full-time as assistant, and at times I have had to work very hard. In the future I can see that I won't be working as an assistant at all. At the moment I work about 20 hours a month. I have not had any normal full-time work as a personal assistant for several years, even if Anna has nothing against that," she says. Anna's younger brother and her father are not on the timetable either, but stand in as required during sickness and holidays.

It is quite normal that, besides the parents and any husband/wife or partner, children, brothers and sisters and other family members are employed as personal assistants.

Kent, born in the mid-1960s, does not want anybody but the family to help him when going to the toilet, or with his finances. "My mother is my personal representative. My sister is my service guarantor, and works full-time as an assistant. My brother and my parents work full-time as assistants. It was natural for my relatives to start working as my assistants, because they had always done so – but previously without remuneration. Before my parents were employed as assistants, the family found it difficult to make ends meet. My mother stopped work so she could help me. My sister, my brother and my father helped as much as they could. My sister was going to school, but had to work in the evenings to help provide for the family. My father sometimes had two jobs," says Kent, with his sister's help.

4.3 Unpaid service from associates

As for the question of how much support and service people receive from other closely associated individuals who receive no financial remuneration, the details in the material are imprecise. To get better answers, we should have defined the questions more precisely. As it is, we often got answers such as "four hours a day" or

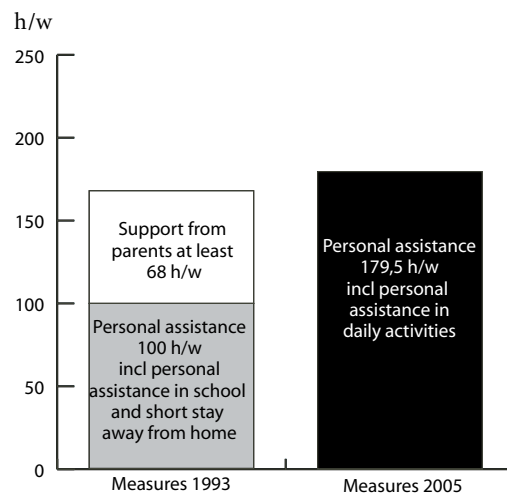


Figure 9. Anna and her care provision in 1993 and 2005

"At all times outside school hours". Several people chose not to answer at all.

Table 1 reveals that the differences between children and adults is surprisingly small. As regards children, people usually say that parental responsibility declines as the child grows older. Many parents of children with disabilities receive a tax-free care allowance as compensation for employment income foregone. A full care allowance is regarded as equivalent to a full-time job, and is often withdrawn, either wholly or partially, when the child is granted personal assistance. It is not clear whether the interviewees took into account any care allowances when providing details of the parental care provision.

In 2005, only a few people said that their parents provide support and service without remuneration.

David lives in group accommodation, but spends three weekends out of four, from Friday evening until Sunday evening, in the parental home. During that time he receives support and service from his parents for which they get no financial remuneration.

Ingemar, born at the end of the 1950s, lives in a villa with his parents. His parents were previously employed as personal assistants, but have now passed the age limit for employment, which at the JAG User Cooperative is usually at 75. The father is his personal representative, and both parents "fill in" with assistance as and when needed, estimated at somewhere over 60 hours a week. Ingemar

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Interval	People born 1975 or earlier			People born 1976 or later		
	1993	1995	2005	1993	1995	2005
0	53%	81%	92%	56%	94%	93%
1–20 hours/week	0	3%	0	0%	6%	0
21–40 hours/week	6%	9%	0	9%	0	4%
41–60 hours/week	9%	3%	0	9%	0	4%
61–80 hours/week	9%	3%	8%	9%	0	0
> 81 hours/week	22%	0	0	18%	0	0

Table 1. Extent of unremunerated care provision from relatives (parents, husband/wife or partner).

has not applied for night-time assistance. Hitherto he has received the help he needs from his parents. All three now want to move to the centre of the municipality. Ingemar and his personal representative are trying, together with the provider of personal assistance, to find a solution as soon as possible.

From the 2005 interviews it is clear that several disabled people receive substantial help and support from their relatives on an unremunerated basis, even if some choose not to disclose a specific number of hours.

Björn was born in the mid-1950s. In 1994 he obtained personal assistance and could then move into his own flat. At that stage he had lived in institutions for 10 years, including three years in group accommodation. Björn has been granted personal assistance for 72 hours a week, and the assistants' timetable is adapted to his own wishes for active leisure time. One consequence of this is that the assistant hours are not sufficient for all the daily things to be done. His mother, in addition to her half-time job as personal assistant, is also his personal representative and service guarantor. She also does bulk shopping, prepares food and packed meals. She also helps him with buying clothes, computer support and so on.

Anna was born at the end of the 1970s. She lives alone in a flat with a small garden. Her relatives stand in as and when needed. "Looking ahead, when we are no longer around, there are some things that need to be sorted out. Currently we help Anna by doing things like bulk purchases of hygiene products, cutting the grass and looking after the garden. If she is going to stay here, somehow this needs to be done by assistants," wonders Anna's mother who is

also her personal representative. The aim is also to recruit several stand-ins, so that the parents can be entirely replaced by assistants. "Even though we like coming here and working for our daughter, she should not be dependent on us," argues her mother.

4.4 Suppose something happens...

Many parents feel that they are irreplaceable for their child's assistance.

"Suppose something happens to me..." says Urban's mother and personal representative without completing the sentence. Urban was born in the mid-1980s. His father is no longer around. "I would like to be more replaceable," says his mother. Her aim is to recruit another service guarantor and to work less as an assistant. But she wants to retain her position as personal representative. She sees that as essential for Urban's life to work properly.

However, the experience of two interviewees who lost their parents shows that assistance does not necessarily fail.

Olle was born in the early 1960s. He lived with his mother who was also his personal representative, his service guarantor and his personal assistant. When she died in the early years of this century, Olle's sister was appointed personal representative, and one of his assistants was given the job as service guarantor.

Bengt was born in the mid-1940s. Ever since he was injured in an accident at work in his twenties, he has lived with his parents. His mother stopped work in order to help her son full-time, and his father was the breadwinner. In 1993 Bengt was granted personal assistance by the mu-

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unicipality of eight hours a day. At other times, the home help service stepped in as needed. Following the assistance reform, Bengt was granted round-the-clock personal assistance. His mother took on the job of supervising Bengt's assistants. Now both parents are dead and Bengt lives alone in his house. His new service guarantor was recruited by the provider of personal assistance. "My mother was an assistant when her health was better. In the early days she worked a lot, and I think we were alone at night. If there was no assistant, and we couldn't find one, Mum had to step in," says Bengt. About the future, he says: "I am living in my own house, and that will continue."

Sometimes there are siblings or associates prepared to take over the parents' work as personal representative, supervisor or assistant.

Tomas' personal representative and mother says: "I am his mother 24 hours a day. That's my job. I have tried and found it doesn't work if I have a job somewhere else. He was granted five hours extra because he has such bad spasms. How do you plan for that? How am I to know when the spasms will start and Tomas needs double assistance? I am just about the only person available for that. If I need to go into town and do the shopping, Tomas' two brothers take over the supervision. I just don't know who could take over my jobs. I sometimes think and hope that one of the brothers, or someone else who knows him well, could take over."

David's mother does not want any of his brothers or sisters to be appointed his personal representative. "I do not want to recruit his brothers or sisters, I am their mother as well and want them to live their own lives," she says.

Many parents say that they would like to be less involved in assistance and just be parents and personal representatives.

Elisabeth's mother, who is her personal representative, service guarantor and assistant, works part-time as a nursery school teacher. She thinks it is important not to be financially dependent on Elisabeth. She would like to hand over the supervisory work to someone else, but feels no one is to be found right now. "It is hard work and an enormous responsibility. But it is important to be able to set Elisabeth's day by day life in the right direction," she says.

Lars was born in the early 1980s. His mother is his

personal representative, his service guarantor and his assistant. "Being service guarantor is a round-the-clock job, something very special. I never go home from work, and always have to be ready."

Görel has left the JAG User Cooperative and has instead engaged the municipality as her provider of personal assistance, and a municipal administrator is in charge of her assistants. Görel's father is her personal representative and her mother often helps out as an assistant. Her mother coordinates the assistance, even though she has no formal supervisory role. She is also the "safety net" for assistance. "When one of them is off sick, Görel wants me to stand in, so that the municipality does not send someone that Görel doesn't know. This happens two or three days a month if all is going well, plus familiarisation for the new assistants of course. Görel does not want entirely new assistants, they must first double up," says her mother.

Several people stated that one benefit of the assistance reform is that they can give support and service to their children and at the same time have the security of paid employment.

Katarina was born in the mid-1960s. In 1995 she was living with her mother, who was also her personal representative. "It really means a lot that parents get remuneration for their work. That means you are a person who does a proper job. Going back to unremunerated work is like saying you are not doing anything of value. For Katarina this is extremely important! She thinks it is very positive that I distinguish between my work and my time off in our time together," says her mother.

Jimmy was born at the end of the 1970s. His father has this to say about his tasks as personal representative, service guarantor and personal assistant: "I have myself chosen, or grown into, these roles. I don't know how to put it, I don't think about it it's just a way of life. It is not obvious, perhaps as a father you do it for the first few years, but after that it is not so obvious. I have a choice, I am not trapped."

Rebecka was born in the early 1970s. Her mother, who is also her personal representative, says that it is a blessing for her to supervise Rebecka's assistance and thus be part of her everyday life, even though she has moved away from home. "One of the advantages of the JAG model is that being close, we can fulfil the various roles," she says.

Pontus was born in the early 1970s. His father feels he has a fine role as his son's personal representative and service guarantor. Pelle meanwhile appreciates the proximity to his parents. "We get together as a family at Pelle's place every Thursday evening, and sometimes Pelle comes to us for Sunday dinner. Sometimes Pelle wants us to go to an indoor shopping centre if I am on duty. We meet up with his mother there, and Pelle can go rolling around by himself with us in the background. He loves that."

4.5 Married couples and partners

In 2005, two of the interviewees were married or in a partner relationship. Several of the interviewees had previously been married or living together. Sometimes the support was shared for a time between the parents and partners, or wife/husband. When the partner or husband/wife disappeared from the scene, in several cases the parents or other relatives remained as the "last lifeline".

Eva was born at the end of the 1950s. Towards the end of 1993 she suffered a severe illness and remained in hospital until the spring of 1994. For the first period at home, she obtained support and service from her partner and the home help service. In 1995 she became a member of the JAG User Cooperative and was granted 116 hours a week of personal service. Her partner worked full-time as a personal assistant and service guarantor, and her brothers and sisters were employed on an hourly basis as personal assistants. By 2005 Eva had separated from her partner. She lives in her own flat, her brother and sister work as assistants, and one of them has taken over a supervisory role.

4.6 Opportunities for release

In this chapter we have shown that many parents naturally reduce their working hours as personal assistants when they see that the child's need for support is met without them. At the same time, the opportunity for the parents to have a secure form of employment as a personal assistant reduces the dependence on allowances, and means a smaller source of worry for the whole family.

Tomas was born at the end of the 1970s. His personal representative and mother who works full-time as Tomas's personal assistant tells the story: "It was hard work before LSS. The municipality sent people who didn't even want to come. I think things are easier now that I can devote myself entirely to Tomas. I used to work full time away from home, even though I was often off sick, and spent the rest of the time helping Tomas."

However, employing parents as personal assistants to their children is sometimes presented as a problem. For example, the Swedish National Audit Office wrote in 1994:

*"In some cases, families can become dependent on assistance remuneration for their livelihood. This may result in young people with disabilities remaining in parental homes as adults, which may restrict their development as self-sufficient people."*⁵

Our investigation shows the contrary – the assistance reform has led to fewer adults remaining in the parental home. In 1993, barely 20 percent of the interviewees over the age of 18 were living in their own homes. By 2005 this figure had tripled. Close to 60 percent of the interviewees over 18 with personal assistance now live in their own homes, and they have a real chance to decide for themselves whether they want support and service from their relatives or not.

The move to her own home made Birgitta more independent, and also improved the relationship with the family. "These days, Birgitta says what she wants more definitely, now that she has freed herself from us, her parents. While she was living at home, she was a cheerful and contented girl, not doing much. Now she gets much more out of life. Birgitta is happy and feels safe with all her assistants – so it doesn't matter who is on duty. Birgitta can travel, she can go by bus to Stockholm and go on a cruise to Åland. She can go and see her grandmother and her cousins any time she wants to. She has friends living in group accommodation, and it is perfectly okay for Birgitta to travel to see them at their place. They can't travel for lack of staff. The whole family can go and see Birgitta and stay over the weekend, we all squeeze in. Birgitta thinks this is great, she is first up in the morning to get breakfast for us," says her mother who is also her personal representative.

⁵ The Swedish National Audit Office, 2004. Personal assistance to people with disabilities

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The personal assistants' experience, attitude to the job, qualifications and personal qualities are of great significance for the quality of support. But it is equally important that the assistance is adapted to meet the needs of individuals. To achieve the ambitions in LSS requires that the assistants are adequately and properly managed.

5.1 The choice of provider of personal assistance

In interview round 2 there was a question whether it was important to be able to choose the provider of personal assistance. In broad terms, all the interviewees answered yes. In particular, many of them thought this was important when the assistance was introduced.

“For Björn what mattered was finding something that was individual and tailor-made – the rest he had already practised in the group accommodation,” says his personal representative. “It’s good that there is a chance to change to another provider of personal assistance if you are not satisfied,” she says, and points out that at one time Björn was dissatisfied, and was thinking about changing his provider of personal assistance. But the problem was later sorted, so it never happened.

Many of the interviewees had had previous bad experience in their contacts with the municipality. Being involved with a user-oriented cooperative, and having some influence over the training of assistants, was for most people a conscious choice.

“Eva would never even open the door to the municipal staff. Now she can ride, walk and swim, just as she wants. The only limitation is money. Eva has great freedom, and wants to manage the assistance herself – and takes pride in doing so,” says her sister who is also her personal representative.

“We thought that the service offered by the municipality was not much good. They didn’t tell us about Kent’s rights. It wasn’t until he started at the Frösunda daily activities in the autumn of 1993 that he found out that he could get personal assistance. Before that, the family had helped him round-the-clock without remuneration, apart from the hours when he was at the daily activities,” says Kent’s sister.

Often it is the contact with an individual official or administrator that determines one’s view of the municipality.

Anette, born in the mid-1980s, had an assistant half time at home and in nursery school from the municipality even before the assistance reform. This worked well, except that the assistant wanted to take breaks at specified times. Anette’s mother had employment as a relative. Then the municipality decided that children should not have employed relatives. When her mother asked how she should then earn a living – she meant that she couldn’t go out to work as she had to help her daughter – the official at the municipality suggested applying for social security. That’s why they chose the JAG User Cooperative when the opportunity arose.

For other people, the choice of a provider of personal assistance seems random.

“When we had to choose for the first time, we chose Frösunda assistance – but they declined, and then we found out about JAG. The municipality was never an option, because as I understand it, they control everything, and Pelle would never have had a chance of self-determination,” says Pelle’s personal representative.

The three people who have changed their provider of personal assistance did not give any particular reason for doing so.

5.2 Opportunities to manage the assistance

All members of the JAG User Cooperative have a service guarantor who supervises the assistants. Being a service guarantor is a partly unremunerated job that involves taking responsibility for ensuring that an individual member has properly functioning assistance, and that a capable assistant is on site at the agreed times. The ser-

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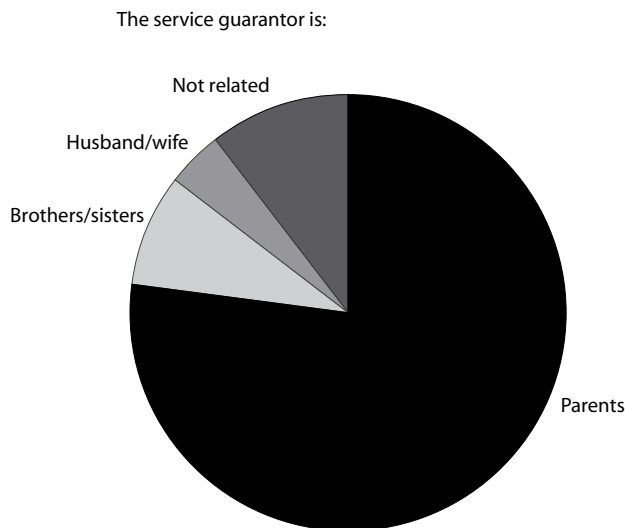


Figure 10. Interviewees' relationships to their service guarantor, 2005

vice guarantor vouches for the assistance being individually designed and being provided on the individual's terms.

The majority of the interviewees' service guarantors are relatives. Of the 49 people who were members of the JAG User Cooperative in 2005, three quarters had their parents as their service guarantors. Eight percent of the users are brothers or sisters of the service guarantor, and four percent are husbands/wives. Ten percent are not relatives, and several more are underway.

In the JAG User Cooperative, it is becoming more usual that people other than parents are appointed as service guarantors and supervisor of the assistants. Often it is one of the assistance who has worked for a while who is offered the opportunity for promotion in the job. It is also becoming more usual for two people, one of whom is perhaps a relative, to share the work. Apart from some individual exceptions, all service guarantors are employed as assistants.

The wish and ambition of the interviewees to take part in managing the assistants is very strong.

Jimmy takes a very active part in deciding who gives assistance, also how and when. "This is something he can decide entirely by himself. Jimmy is involved in the entire employment procedure. He selects who will work, and sometimes the timetable has to be changed to meet Jimmy's

needs. Jimmy is as involved as he can be, given his circumstances," says his father.

Björn has experience of both care homes and group accommodation. During the time he was in institutions and group accommodation, his mother accompanied him between various activities each week, swimming, bowling, riding and theatres. Today, as his personal representative and service guarantor, she can help her son decide about assistance. She sees a great difference compared to the years he spent in group accommodation. She tried to suggest suitable activities to the staff, but nothing ever came of it. "The staff at the group accommodation thought that what really mattered was that the people living there should share mealtimes and drink coffee. But for Björn what really mattered was having something to do that was adapted to his needs, that the activities suited him, and helped develop what he is good at. That he doesn't always have to take other people's needs into account," she says. Björn joins in and chooses which assistant will be appointed. His mother describes how things might go at a recruitment session: "First I make an initial choice of two or three possible people. They get a chance to meet Björn and we take photographs of them. When they have gone home, Björn and I look at the photos. I ask him if he wants any of them to come back. Björn selects by pointing or holding up the photograph of one of the assistants."

Daniel was born in the early 1980s. If a new person starts work as an assistant, I look at Daniel's reaction," says his mother who is also his personal representative. "Is he happy, angry or sad? He may even shove or kick in dissatisfaction. When we appointed a new assistant, he or she is on probation. Daniel is always curious about new people. He is keen when the assistance is provided to him as a person in his own right. If not he just becomes passive. Obviously he wants to be involved!"

Pontus was born in the early 1970s. He lives in his own flat. "In everyday life, Pelle is in charge. He shows us when it's time to wash, drink a beer or a cup of coffee. When it's time to sign a contract for new appointments, he doesn't bother to be there, but he always takes part in the appointment interviews. Afterwards we usually bounce around ideas about the person. Pelle holds his thumb up or down. If the person passes and gets a thumbs-up, we usually call

them to a second interview,” says his father who is also his personal representative.

Gunnar was born in the early 1970s. He has no personal representative. Gunnar answers the questions himself, but because of his communications handicap his mother, who is also his service guarantor, helps him to formulate the answers. “Gunnar is involved in the entire appointments process. He writes the job advertisements himself as and when needed. It is important for Gunnar that the assistant is someone with similar interests,” says his mother. “Personally I have no problems understanding Gunnar. He expresses himself verbally in his own way. Gunnar is very determined. He doesn’t give away, and tries to get us to understand what it is he wants. He may sometimes need help to understand the consequences. But we always sort out everything together. It’s not possible to make decisions over his head. As his mother, I have tried, but realised it’s a mistake. Gunnar knows what’s going on and keeps control of all aspects and decisions in his life. If he needs help he calls me.”

Dagny was born in the mid-1940s. She does not have a personal representative. Her husband is her service guarantor. Dagny has a progressive disease, but is still able to organise her assistance, and feels that this is working well. “As long as I can speak I want to organise things myself,” she says.

However, most of the interviewees have considerable communications handicaps and intellectual impairment. For these people to attain the LSS ambition of self-determination, their assistants have to be given the right guidance.

Martin was born in the mid-1980s. He has just moved into his own home and has double assistance. His objective is to be able to choose which assistant will give assistance in different situations, for example when eating. Together with his mother who is also his personal representative, he is trying to find a system for this – for example pictures that he can point to. The personal representative is convinced that Martin’s participation will increase as he gets more opportunities to choose. In several ways, Martin’s need for double assistance makes life more complicated for the assistants. “It’s difficult to find assistants who can work with

other assistants without losing the focus on Martin. The double assistance means managing more rigorously and having clear rules for every situation. Now that Martin has moved away from home it is a bigger commitment, and we need keep monitoring the situation to ensure that Martin remains in control -- not the assistants. It was easier to keep an eye on things when Martin was living at home. I think that as his representative and supervisor we must be very clear, and encourage the assistants to understand how important self-determination is for Martin,” says Martin’s mother who is also his personal representative.

Simon was born in the early 1980s. “Some personal assistants need more guidance than others, and others are too determined to keep control. New assistants often want to show how good they are, and in those circumstances Simon can’t really keep up. It is important for me to be very clear, and to follow up issues when things are calm. I try to encourage a feeling for the nuances in Simon. It is important to address issues to do with values and attitudes,” says Simon’s mother who is also his personal representative and service guarantor.

5.3 Recruiting assistants

All the interviewees make the point that the quality of assistance depends crucially on the person providing it. Relative or not, experienced or newly employed, attitude, qualifications and personal characteristics are all very significant. Nearly all need assistants who have been trained. The time needed for training varies, but it generally takes at least one month before the assistant can work on his or her own. As the demand on the assistants’ personal suitability is high, and the “personal chemistry” between user and assistant must work, it may take several months from the time when one the assistant leaves and the new one can work to the regular timetable. Many of the interviewees state that the recruitment process is very stressful.

Pelle’s father is the service guarantor for his son’s assistants. Initially he had to work a great deal as personal assistant, full-time or more, because of the recruitment problems. But over the years he has become better at recruiting assistants who are suited to the work. These days he only works extra as an assistant in order to provide cover for holidays, parental leave or sickness. “It took a while

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for us to sort out the assistance, until I understood that it was not a good idea to employ people aged below 30. Below that, it is too much of an ego trip," he says.

The supply of personal assistants seems to be very sensitive to the state of the economy, and also varies a great deal depending on where people live. For those who want special skills, the situation is also difficult. Poor public transport can also be a problem.

Rasmus lives out in the country. His assistants' work timetable is adapted to his needs and daily rhythm, and not to the times of buses, as his assistants want. His personal representative, also his mother, explains: "When the assistance is working smoothly, it's wonderful. Rasmus's life is as good as it gets. I can't see how Rasmus could manage in any other way than with personal assistance. Collective solutions are no alternative for him. The problem arises when we need to recruit a new assistant. The latest recruitment took five months. When stand-ins are needed at short notice, it is nearly always Rasmus's relatives who have to step in as he needs assistants who know what to do."

5.4 Assistance at school and in daily activities

Among the younger people, as mentioned earlier, it was quite usual to have personal assistance during school hours even before the assistance reform. During "free

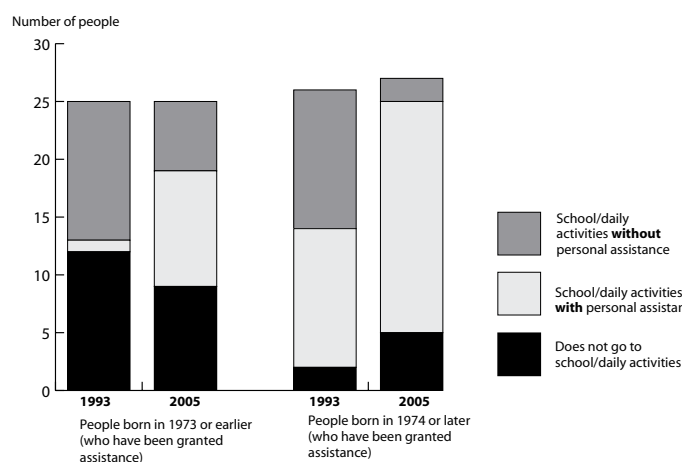


Figure 11. School and daily activities for the interviewees who had personal assistance in 2005

time," in other words the remainder of the week's 168 hours, it was generally the parents who provided the necessary support.

By 2005, the proportion of assistance during school and daily activities hours was smaller in this group compared to 1995, but this is primarily because the total number of assistance hours has increased.

The change in the law in 1996 which limited the entitlement to personal assistance at school and in daily activities appears therefore not to have affected that many of the interviewees.

One of the problems that arises for those who have not been granted personal assistance in activities is that they have to sort out their service needs in some other way if for any reason such as sickness they cannot take part in the activities.

Adam has not been granted personal assistance for his daily activities. This is a problem when he is ill and cannot attend the activities as planned. His regular assistants have their working hours set to evenings, nights and weekends, and therefore cannot work during the day on weekdays, reports Adam's mother and personal representative. "The municipality have said that they will happily provide assistance to Adam whenever he is ill, or during the summer weeks when the day centre is closed, but this doesn't help us much," says his mother who is also his personal representative. Adam's assistants, even stand-ins, need to know what to do, and the only stand-in who can do this and step in during the daytime is his mother.

Unlike school, the daily activities are voluntary.

Andreas has stopped going to his daily activities. He made the decision himself. "In order to stop going to the daily activities Andreas finally withdrew with his personal assistant from the centre. As his representative, I had to ring the daily activities centre and tell them he had stopped: Andreas suffers, he can't cope with joining in all the small excursions," says his personal representative. "Now Andreas can go wherever he likes, it is fantastic personal freedom. Ice hockey, meals, going on a spontaneous excursion. He loves going to watch sports training sessions, he likes fishing, especially from a boat. He usually trawls at a leisurely pace," says his personal representative.

6. PRIVATE LIFE AND INTEGRITY

The user's integrity is one of the cornerstones of LSS. However, personal assistance means that for most of the hours of the day there is another person close by. How the interviewees experienced this stress and whether they have seen any change since 1994 varies.

In interview round 2 we asked whether assistance meant that the interviewee was able to reveal personal matters to a lesser extent or to fewer people, and whether this had changed over time. This question applied to assistants, allowance administrators, the staff at the Social Insurance Agency and other officials. We also asked those who have increased remuneration whether they found the description of needs, and the detailed financial reporting, as a violation of their integrity and privacy.

Many interviewees said it was stressful having to describe their needs to an official at the Social Insurance Agency when applying for increased remuneration, while others felt negatively about having to account for how they had spent the assistance remuneration.

"In my daily life I now have to give out more information about my personal circumstances to more people because assistants have been employed for most of the time, whereas previously it was just the family. But it has also enriched my life. There are more people around me and in my personal network. There has been more contact with officials at the Agency, but less with LSS administrators and temporary staff, as I no longer need the care provision as much as previously," says Adam through his personal representative.

Having personal assistance means having another person close by pretty well constantly. This naturally also affects other people living in the same household.

"Our parents, with whom Kent shares the flat, feel that the assistance has a negative effect on their private life. They would like more private life. That makes it hard for him to employ more outside assistants," says Kent's sister who is his service guarantor. "Our parents are now in their 70s. Kent and I would like to employ more younger outside assistants for Kent, but it's difficult. Kent would like to go on living with his parents, and they too would like to go on living with him. But they would like us to get a larger flat

with two entrances, so that they and Kent would each have a separate part."

Daniel was born in the early 1980s. His legal representative does not think that the assistance reform means he is revealing his personal circumstances to any lesser extent or to fewer people than before. If anything, it has got worse since he became an adult. "The whole family feels exposed. When he was little, only the school and the rehabilitation centre were involved," she says.

For Björn, the opposite is true. "At the group accommodation where he used to live, there were about ten staff who needed to be kept informed, plus all the new staff joining. So now, thanks to the assistance, there are fewer people," says his personal representative. Björn does not regard having to report how he spends the assistance remuneration as violating his integrity and privacy. "At the same time, it is not normal to have to describe one's needs down to the smallest detail and then be checked out."

Görel has purchased a small terraced house not far from her parents which the municipality has adapted. "Görel has much more self-esteem since leaving home. She doesn't keep having to ask her mother for help, and can live on her own like other people of her age. She has the chance to live a normal adult life, and can let her boyfriend stay overnight without asking her mother for permission," says her mother. Görel finds it insulting having to describe her needs to administrators at the Social Insurance Agency and the municipality. "She doesn't want to tell anybody. It has if anything got worse for Görel, as she is now in the adult world and is more conscious of what is required of her in order to get assistance hours," says her mother.

Birgitta's personal representatives think that these days there are fewer people to whom she must reveal her personal circumstances. "There used to be group meetings of staff and pupils at the school boarding house where Birgitta lived when she went to school. Birgitta might be left

out of the group, and it is not a pleasant feeling to be discussed by a staff group. Now if anything happens, we know exactly who was working, and can take it up with the right person," says her mother and personal representative. Her mother found it very hard having to describe Birgitta's needs in order to get additional remuneration. "I shudder just thinking about it," she says.

Anette was born in the mid-1980s. At the school, they wanted a book on every pupil, but Anette and her mother refused. "No one will be any the wiser from reading Anette's journal, there is so much in it about illness, but that has nothing to do with Anette as a person. I can try to limit the information about Anette, but we live in a small place where everyone knows everything about everyone else, and we have never "hidden" Anette, we are not a family wanting to keep ourselves to ourselves. We don't feel our integrity and privacy have been violated either, apart from that book in the school," says Anette's mother who is also her personal representative. It was also stressful when Anette applied for increased assistance remuneration. "You had to tell them everything that is bad, and nothing of what is good," she says.

Some of the interviewees found it very hurtful when so-called "experts" gave their views on how people with disabilities and their relatives ought to live.

Rosita was born in the early 1980s. She was injured in an accident at the age of 10. Her mother and personal representative says: "For example, there was a doctor at the hospital just after Rosita had sustained her injury. She thought that I spent too much time at the hospital, and that Rosita needed more space."

Roger receives assistance 210 hours a week. This means that a rather large circle of people round him need to know all about his private life. "It is important that this information stays within the circle," says his mother who is also his service guarantor. Some other things for which Roger needs assistance are, according to his mother, strictly personal. These are done only by herself.

For those who were children when the assistance reform was introduced, and had previously mostly received support and service from relatives and associates, the assistance has often meant that as they grow older, they have had to reveal more about their private lives.

Pontus was born in the mid-1980s. His personal representative and mother says that more and more people have become involved in his life now, but this is a conscious choice. The difference now is that Pontus decides for himself what to give out. "Thanks to personal assistance, no one else decides," she says.

Helge was born in the mid-1940s. He agrees that there are not fewer people who know things about him, but now he can decide himself what information he gives out about himself, and to whom.

Ingemar was born at the end of the 1950s. He found it insulting when the Social Insurance Agency officials visited him. "Just think, they wanted to know exactly how long it took to go to the toilet," he says.

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Regular support from a limited number of people provides continuity and security, which in turn leads to a better chance of successful rehabilitation and training. Well-functioning personal assistance also reduces the need for nursing care.

The interviewees are unanimous: the need for nursing care and the number of hospital visits has fallen in the last 10 years. Improved health is attributed to the security and continuity of assistance.

Following the assistance reform, personal assistance can, with or without care training – as relatives always could – give support and service that was previously considered to be skilled care, such as taking medicine, tending a wound or a stoma, using breathing aids, or doing physiotherapy. It is the doctor in charge of the treatment who decides in each individual case what is self-care, and therefore can be done by personal assistance.

Katarina was born in the mid-1980s. She has a progressive disease which means that her bodily functions will gradually get worse. A minor cold often leads to pneumonia. “It is only thanks to personal assistance that Katarina is alive today,” says her mother.

Olle was born in the early 1960s. Before the assistance reform he lived with his mother and was granted 56 hours assistance a week. At other times support and service came from his mother. As a form of relief for his mother he stayed in hospital at regular intervals. In 2005 Olle’s service guarantor talked about the changes: “Olle has many good drugs, but he also needs skilled care. Instead of, as previously, spending months in hospital, it is now just days. Thanks to personal assistance, Olle can live in his own flat.”

For Andreas too, assistance has meant better health. “He gets a higher quality of care, and his personal assistants know how to handle Andreas’s epileptic convulsions. They can even avert the convulsions by calming him down,” says his personal representative.

“While in group accommodation, Björn was ill for two or three days twice a month. The people living there infected each other with colds and stomach upsets. If one per-

son became ill, they all became ill,” says Björn’s personal representative.

Pontus was born in the mid-1980s. Before he moved to his own flat he spent every other weekend in a short stay home. This arrangement worked well when his assistants were with him at the short stay home, otherwise it didn’t. “He has tried, but the medication didn’t work without assistance,” says his mother who is also his personal representative. His personal assistants understand Pontus’s medical needs, which means they can prevent a lot. “Otherwise he would be in hospital a lot,” she says.

The possibility of getting continuity in training through assistance is said by many to be very important.

Benny has got better and has less and less need of care. His personal representative believes this is entirely due to personal assistance. “Thanks to assistance he can train a great deal and freely,” she says.

“If we hadn’t been assistants to Lotta, then she wouldn’t have been able to train, that’s been possible thanks to assistance. Thanks to that she has got back much quicker, say the nursing staff we met. It was important for her to be able to go several times a week and have continuity in the training. That also means that the healing has been faster. Communications were also very important in the beginning when she couldn’t talk. Things have improved very fast, to the point where she can now talk,” says Lotta’s mother.

Well functioning personal assistance provides continuity and security. It’s a question of getting the day-to-day routine working properly, wherever you are.

Daniel needs plenty of sleep, to listen to music, and the Lord of the Rings. “Thanks to personal assistance, Daniel gets lots of time to listen,” says his mother and personal re-

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presentative. "Daniel's health is better because he doesn't get stressed. The day is planned out entirely according to how Daniel feels. As a result, Daniel has fewer convulsions and needs fewer hospital visits," she says.

Olof was born in the mid-1980s. He easily gets convulsions if there is anything new or he is worried. This happened, for example, during the first visits to the short stay

home. Olof's parents talked with the manager, and now Olof is now accompanied by a personal assistant at short stay homes. The fact that Olof's health is better owes much to assistance, says his mother. "Compare this with his convulsions at the short stay home – that was his reaction to communal housing. It is not a good alternative for him. Olof needs to be by himself, he needs peace and quiet," she says.

8. CONCLUSIONS AND DISCUSSION

Personal assistance gives the freedom to create your own life. At the same time, assistance is sometimes perceived as being less secure than more institutionalised forms of support. To avoid the risk that the interviewees and other people in some circumstances lose out on this freedom, it must be clear that assistance works well even without the participation of relatives.

Nearly all the interviewees have considerable communications handicaps – but given the right circumstances, they can all achieve self-determination in individual situations. Those who lack the normal power of speech have other ways of expressing themselves that can be interpreted by the people closest to them.

The majority of adults among them have a personal representative. Usually it is one or both parents. For those with communications handicaps who need support in making decisions, it is essential for self-determination to be able to communicate with one's personal representative.

Before the assistance reform, over 80 percent of the interviewees lived in shared households with their parents. A large part of their support was given by the parents, who did not receive any financial remuneration. The community facilities on offer were mainly short stays. As the purpose of short stays is to provide relief for family members in shared households, the use of this facility fell sharply in the years to 2005, as more people now live in their own homes.

The assistance reform has made it possible for the adult interviewees to live in their own homes. In 1993, barely 20 percent of the interviewees over the age of 18 were living in their own homes. By 2005 this figure had tripled. Nearly 60 percent of those interviewed over the age of 18 and receiving personal assistance now live in their own homes.

Among those who lived in their own homes in 1993, some had assistance, while others received support and service from the home help service or from relatives, with or without remuneration. By 2005, the employment of relatives, the relief service and the home help service had broadly ceased.

Even before the LSS reform, many of the interviewees had personal assistance. This is probably because these persons' needs presupposed such individually designed personal support, which could not be provided in tra-

ditional support forms such as group accommodation, the home help service, etc.

It is sometimes argued that parents who are employed as their child's personal assistant can become financially dependent on the child. But it should not be forgotten in this context that in many cases the parents had previously given the same support without financial compensation. This created a dependency on allowances, while at the same time individuals had limited possibilities of getting equivalent support in other ways. Given that parents can now be employed on the same terms as other assistants, they too are replaceable. The interviews also demonstrate that the assistance reform has led to people being less dependent on their parents: In 2005, fewer parents were working as assistants than in 1995.

All the interviewees felt that the assistance had had a very beneficial effect on their state of health. The need for nursing care, and the number of hospital stays, has declined over the last 10 years. Furthermore, the continuity of training made possible by assistance has led to faster rehabilitation for people injured as adults.

In 1995, the answers were unanimous on the view that institutional care or group accommodation were not conceivable alternatives to personal assistance. The majority of those interviewed were getting very strong support within their families, and their relatives had previously given them the care needed, regardless of whether they were receiving remuneration from the community or not. Broadly speaking, there were no disadvantages in assistance. The interviewees were more concerned about what might happen if they lost their newly-won freedom: Relatives would once again be brought to their knees with exhaustion. The whole family's existence would be shattered.

By 2005, the view of assistance had changed somewhat. Almost all regard personal assistance as invaluable. Even so, three people have switched their per-

sonal assistance to service in group accommodation. Of these, two gave as a reason that their relatives, as they put it, “could not see any other way out”. There are hints that several other people are worried about the future, and are weighing up various alternatives. In most cases, this is because the relatives do not rely on assistance, in its current form, continuing to work without their participation.

An important conclusion in the report is that the quality of assistance depends on how it is managed. The deputy supervisors/service guarantors must receive support from the provider of personal assistance, including training and guidance to enable them to do their work. If the service guarantor is worried about upsetting the assistants, and does not dare to, or does not want to, impose reasonable performance standards, this will inevitably lead to a degradation of quality for the person entitled to assistance.

In order not to lose the greater freedom and quality of life of people with very extensive disabilities that has been built up during these years, the community must recognize the need for readiness and the management of assistance. It is important that there is scope in the remuneration to recruit as managers people other than relatives, so that the assistance will function long-term, even for someone not able to be a manager.

It must be made clear that the relatives of people entitled to assistance are replaceable. Otherwise there will be fewer possibilities of choosing personal assistance

for people with intellectual impairment. Even though people might in fact wish to continue receiving personal assistance, they may feel compelled to move to group accommodation when the parents grow too “old”.

* * *

In conclusion, some reflections from the interviewees about what assistance means to them:

“Jimmy can go out at any time of day or night – that alone is a big difference. He would really go into decline if he had to go back to the old folks.”

“Things are definitely much better. Helene can do what she wants when she wants, without having to do things as a group. She now has a good life, and things are working really well based on Helene’s needs and on her own terms.”

“Assistance is invaluable. It’s the best thing they’ve thought of. I don’t know how things would be otherwise. I suppose I would have to live in some home. With personal assistance, I can do it all – go shopping, visit the grandchildren. In May, I had to stop driving my car, but now, thanks to assistance, I can still drive. I can do the crossword, I can baby-sit the grandchildren, I can do my hair and makeup every day.”

Appendix 1. Questionnaire for interview round 1

1. Before/after LSS, did you have:

- a. Personal assistance from the municipality, number of hours/week
- b. Employment as assistant, salary/month
- c. Relatives as personal assistants, number of days/year without remuneration, number of hours/week employed relatives (municipality in number of hours/week, salary/month/County Council number of hours/week, salary/month)
- d. Home help service from the municipality
- e. Relief service (municipality, in number of hours/week/County Council, number of hours/week)
- f. Short stay home, number of days/year or month
- g. Short stay family, number of days/year or month
- h. Short period of supervision for young people, number of hours/week
- i. Nursery school, with special resources = extra staff in the group, number of hours/week
- j. Special school, with special resources (extra staff in the group, number of hours/week/pupil assistant)
- k. Day centre, with special resources (extra staff in the group, number of hours/week/assistant at the day centre)
- l. County Council, special social services etc
- m. Group accommodation
- n. School boarding house
- o. Summer camps/camps, County Council, number of days/year
- p. Free time after school (municipality/County Council, number of hours/week)
- q. Hospital as relief/short stay, number of days/year

2. Before/after LSS, did you have:

- a. care allowance
- b. Home nursing care allowance, SEK/month

County Council

- c. Home care allowance, SEK/month (not after LSS)
Municipality/County Council
- d. Disablement allowance, % of base amount SEK/month
- e. KBT (member or household)
KBH (member or household)
- f. Social security

3. Do your parents have any employment outside the home?

- a. hours/week
- b. salary (optional)
- c. A-kassa/other labour market measures (training or similar)
- d. Have your parents been off sick/stayed home with sick child, number of days/year

4. What would happen if personal assistance for you were to cease?

- a. Ceases at night time – consequences if personal assistance ceases – consequences
- b. Parents home more often for “sick child”?
- c. Right to personal assistance at the day centre ceases
 - Stop going to day centre?
 - someone has to be at home?
- d. Financial and practical consequences
- e. What relief does the family get?
- f. How much free time does the member get?
- g. Employed relatives
- h. Other assistants
- i. When the member has changed the form of living,
 - Institution instead of personal assistance?

Appendix 2. Questionnaire for interview round 2

Hi,

Here are the questions I would like us to discuss:

The role of your representative

- How do you communicate with each other?
- In what way (specifically) are you able to reach decisions with the help of your legal representative?

Your opportunities to manage assistance:

- To what extent can you yourself make decisions about who gives assistance, when, where and how it is given. How actively involved do you want to be?
- What opportunities do you and your legal representative have to influence the form and quality of assistance?
- Is there anything negative/does not work well in the assistance?

The choice of provider of personal assistance

Is/was it important to be able to choose?

Organising assistance with a personal representative – service guarantor – assistant

- How do things look today ... and in the future?
- How do your relatives view their tasks as personal representative/service guarantor/ assistants? How much did your relatives work as assistants in the beginning? How much do they work now?
- Your housing situation today ... and in the future?

Integrity and privacy

- Has the assistance meant that you now have less need to give out your personal circumstances, or to fewer people? Has this changed over time? This question applied to assistants, allowance administrators, the staff at the Social Insurance Agency and other officials.
- If you have requested increased remuneration: Did you feel that having to describe your needs in order to get increased remuneration was in any way a violation of your integrity and privacy? Is having to account for every krona a violation of your integrity and privacy?

Health

Has the assistance led to better health/reduced need for “care”?

Before LSS came into force in 1994

I would also like to talk a bit about what it was like for you and your family before you received assistance, what different measures the municipality offered you etc.

The JAG Association is an national non-profit association for people with multiple major disabilities and intellectual impairment. The association is organising a project, with support from the Swedish Inheritance Fund, to gather and disseminate information about personal assistance to people with intellectual impairment.

In 1995, which was one year after the introduction of personal assistance in Sweden, 66 people were interviewed, both children and adults, about life before and after the reform. All these people had very extensive disabilities and a great need of support.

Ten years later, the same people were interviewed again. They answered questions on topics such as self-determination, integrity, privacy, and health. Their accounts form the basis for this report which describes how life has changed for some pioneers of personal assistance in Sweden.

"I couldn't have managed without personal assistance. Other people used to decide so much for me, now it is nice to make my own decisions."

Robert, aged 45



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