

The price of freedom of choice, self-determination and integrity

A report from the Knowledge Project:

A cost analysis of different forms of support and service
to people with extensive functional impairments

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This is the first report from the Knowledge Project, a three-year project sponsored by The Swedish Inheritance Fund and run by JAG, with the aim of contributing to the assistant reform for people with extensive functional impairments, one of which is an impairment of the intellectual abilities. The project is also described on the JAG website: www.jag.se

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Summary

The purpose of this report is to provide an economic analysis of the personal assistance reform, the aspect of the disability reform that has attracted the most attention. In addition, more than any other measure it has meant a realisation of the intentions underlying the reform: freedom of choice, self-determination and integrity. The report is based on a cost comparison of a number of group homes for people with extensive functional impairments, and how many hours of personal assistance those resources could cover, as well as review of existing statistics and previous inquiries. The report also contains a brief presentation of a new inquiry into how the support and service have evolved for a group of individuals with extensive functional impairments from 1993–2005.

Our comparison of the personal assistance and group home measures shows that the cost of an individual with extensive functional impairments in a group home often exceeds the cost of personal assistance. This is in spite of the fact that personal assistance often leads to greater flexibility and freedom of choice for the individual.

Consequently, this report shows that there are no grounds for the concept of offering people with extensive needs for support and service alternatives to personal assistance in order to mitigate the increasing costs. When comparing, the most commonly proposed measures to mitigate the increasing costs turn out to be more expensive than personal assistance.

The statistics in the field indicate that since the early nineties, there has been a growing need for support to people with extensive functional impairments, manifested by a general increase in demand for various measures. Both as regards the number of people receiving support and the cost, personal assistance is part of the increase. The number of people entitled to assistance is now primarily growing in the older age groups in client category 3. Our own inquiry shows that before the reform, many people had their needs for care and service met through unpaid work by relatives. In addition to those, they were often dependent on a large number of different support measures. They have now been replaced by personal assistance. Therefore, the cost of the assistance reform is also the price we pay for increased equality for those women who previously represented the lion share of the care provided to close relatives with functional impairments.

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1. INTRODUCTION

This chapter describes the purpose, methodology and contents of the report. We start by relating the background to the assistant reform and the other support measures, like LSS, HSL and SoL that are being discussed.

1.1 Background

Support measures according to LSS and LASS

The disability reform that was implemented in 1994 lead to the introduction of two new pieces of legislation – the Act (1993:387) concerning Support and Service for Persons with Certain Functional Impairments (LSS) and the Assistance Benefit Act (LASS, 1993:389).

The new legislation established that people with functional impairments have the right to govern their own lives. According to LSS, the objective is to ”promote people’s equality in living conditions and full participation in society. The work must be based on respect for the self-determination and integrity of the individual.”¹

The support shall provide good living conditions for the individual. The LSS target group is divided into three client categories:

”people

- 1 with an intellectual disability, autism or a condition resembling autism,
- 2 with a significant and permanent intellectual impairment after brain damage in adulthood due to an external force or a 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 significant difficulties in daily life and consequently require extensive support and service.”²

LSS is a law of individual rights. It means that anyone included in the client categories that fulfil the criteria

for the specified support, has the right to receive the support he or she requests. An application rejected by LSS can always be appealed in the administrative courts. LSS encompasses the basis of the disability reform and regulates the right to support.

LSS provides the right to ten defined support measures: counselling and other personal support, personal assistance and assistance benefit, companion service, personal contact, relief service in the home, short stay away from the home, short period of supervision for schoolchildren over the age of twelve, living in family homes or homes with special service for children and young persons, residential arrangements with special service for adults or other specially-adapted residential arrangements, and daily activities. According to LSS, the municipalities are responsible for the support measures, except for the counselling and personal support measure, which falls on the county council.

LASS regulates the right to personal assistance benefits. The objective and policy of LSS also apply to LASS.

The right to personal assistance is the part of the disability reform that has attracted the most attention and probably the one measure that really has made possible the realisation of the intentions underlying the reform. It is one of the rights included in LSS. The cost of personal assistance according to LASS is shared equally by the municipality and the state, and the benefits are granted by the Swedish Social Insurance Agency.

Anyone who is not eligible for assistance benefits according to LASS, but who still have a need for, and the right to, personal assistance, may be granted benefits for personal assistance in accordance with LSS (9§2). This applies to persons who have basic needs not exceeding 20 hours, or who need temporary personal assistance.

¹ Prop. 1992/93:159 s. 44 2

² Sections 1 and 7 in the Act (1993:387) Concerning Support and Service for Persons with Certain Functional Impairments

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The municipality grants personal assistance according to LSS and pay the entire cost.

The introduction of LSS and LASS constituted a major change in perspective, manifesting a humanistic approach and an environmentally related view on disabilities.

At the heart of the legislation is equality for all and the fact that people with functional impairments no longer are considered passive recipients of other people's care, but rather active individuals who are able to demand the support that they feel they need. The support is provided on the initiative of the individual, and in the case of personal assistance, the individual shall have a major influence over how, where, when and by whom the service is provided. There is also a clear gender perspective and a notion of fairness underlying the assistance reform. The ambition of the legislator was that the people, often women, who previously provided continuous daily care to persons with functional impairments in the form of unsalaried work, would now receive a salary and pension plan.³

The legislation was amended several times over the first few years. For example, the requirement that basic needs should amount to an average of at least twenty hours per week in order for anyone to be eligible for assistance benefits according to LASS, was added in 1996. This meant that the target group for state benefits for assistance was more strictly defined than previously. In 1997, a lump-sum payment was introduced for anyone eligible for assistance. As this amount does not cover the costs for all assistant users, they also opened a possibility for all assistant users to apply for a twelve-percent increase of the lump-sum, if there were special circumstances.

Unless otherwise specified, we will henceforth use the terms "personal assistance" and "assistance benefit" when referring to support granted by the Swedish Social Insurance Agency. We have not reviewed the municipalities' costs for personal assistance in detail, as it is not always apparent what relates to the first twenty hours and what relates to other funding provided by the municipality.

Support measures under other legislation

In addition to LSS and LASS, support is provided to people with functional impairments, primarily under the Social Services Act (SoL). According to the Social Services Act, people with functional impairments can be granted home-help service, daily activities, residential arrangements, companion service, relief service in the home, short stay away from the home, personal contact, etc. The Social Services Act is not a rights law in the sense of the LSS. The law does, however, govern the right to support benefits. The measures should guarantee a reasonable standard of living to all citizens. This could mean that support is granted for other aspects of life, for example help and support in the home and care if it is not provided by other means. The organisation and implementation of the support measures may vary between different municipalities.

The Healthcare Act (HSL) regulates measures for the medical prevention, inquiry and treatment of illnesses and injuries. The county council is responsible for providing good healthcare for the inhabitants of the county.

Cost development for LASS

Both the number of people eligible for assistance and the average number of granted hours have, in spite of amendments to the regulations, increased steadily since 1994. The increased cost of personal assistance has led to a debate about whether the support is granted and implemented correctly. In 2004, the government appointed a parliamentary inquiry, the Assistance Inquiry, to perform a general review of personal assistance. The directives made clear that the inquiry should analyse the causes behind the increasing costs and propose measures for mitigating and stabilising them, as well as improving cost control.⁴

The debate has seen arguments from several different perspectives. The user community highlights the improvement in quality of life, freedom and independence produced by the assistance reform, and argues that the money is well spent. Representatives of the healthcare

³ Inger Claesson Wästberg, 2004

⁴ Social Affairs Ministry. Dir. 2004:107

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sector also stress the quality aspects, but argue that different staff groups' influence must be strengthened, which would lead to gains in quality and synergies. It would concern everything from the work environment to the operation of training and supervising. The authorities that reviewed the reform have analysed it and propose several ways of mitigating the growing costs by amending the regulations and their interpretation. In a report from 2004, the National Audit Office proposed to limit the target group as they felt that people with reduced autonomy rather should be living in group homes.

The reasoning was that those who need support in their decision-making could not benefit from personal assistance. They also argued that the municipalities shirked their responsibility to expand the number of group homes by pushing the burden of funding onto the Swedish Social Insurance Agency, and argued that personal assistance is a much more expensive measure for society as a whole, compared to residential arrangements with special service.⁵

1.2 Objective

The objective of this report is an economic analysis of the personal assistance support measure.

- Is personal assistance more expensive than other forms of support and service? Are there any grounds for the statement by the National Audit Office that personal assistance is a more costly measure than placement in residential arrangements with special service?
- Are the increasing costs for personal assistance steeper than for other forms of service and support? Why is the assistance reform so much more expensive than was predicted and why have the costs not been mitigated?

Our ambition is to ask relevant questions outside of a theoretical aspect, from the perspective of the users themselves. Our starting point is to keep the intentions of the assistance reform; providing the individual with the power to shape his or her own life.

1.3 Methodology and material

Our work primarily concerns personal assistance on the whole. In comparing the costs of personal assistance to alternative measures in chapter two, we have, using the experience of the JAG members themselves and in the light of the debate about increasing costs, focused on measures for people with extensive functional impairments and reduced autonomy. The bases of the report comprise both public statistics and material from our own surveys.

Chapter two – personal assistance and other support measures

In chapter two, we compare the costs of personal assistance to other support measures for people with extensive functional impairments. We reviewed the arguments from the National Audit Office and looked at the costs of various measures at an individual level. We then examined the amount of personal assistance that could be offered at the same cost per individual as for group housing, for people with extensive functional impairments.

We contacted four municipalities where the cost per person in special housing according to LSS was lower than the national average in 2003. This was done in order not to over-estimate the costs of the group homes in question. In those municipalities, we chose to study one or two group homes where we were told the users had extensive functional impairments and were in major need of support and service. In our calculations, we compared the cost and staffing of the group homes to personal assistance. The weekly cost per person in each group home was divided by the average hourly cost of personal assistance. The result constitutes the number of hours of weekly personal assistance that could be provided at the same cost as for the group home.

Unless otherwise stated, the information is based on a survey among the civil servants in the participating municipalities. The questionnaire can be found in appendix one. Where appropriate, the information has been supplemented with phone interviews with the unit

⁵ National Audit Office, 2004

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managers, or equivalent, of the group homes. In one group home, we were unable to obtain the necessary supplemental information from the people responsible. Consequently, it was left out of the survey.

The four group homes in the report are located in Eskilstuna, Skellefteå and Uppsala. We do not reveal the names of the group homes out of respect for the integrity of the users.

Chapter three – support measures and costs

In chapter three, we look at the use of various measures in accordance with LSS and compare them to other support measures, both as regards time and costs. We also tried to see if we could find traces of "transfer" of costs or people between different systems; if the cost increase is limited to only personal assistance; and if there may be demographic, ideological or other underlying causes.

The National Board of Health and Welfare is the public body in charge of the official statistics of municipal support measures for people with functional impairments. Any statistics concerning personal assistance benefits according to LASS are the responsibility of the Swedish Social Insurance Agency. The National Board of Health and Welfare provided information about the number of people and costs of measures according to LSS and the Social Services Act, while the number of people eligible for assistance and the costs of assistance benefits according to LASS are taken from the Swedish Social Insurance Agency. The Swedish Association of

Local Authorities and Regions (SALAR) also keep statistics of costs of measures for people with functional impairments, and they are more or less in line with the information from the National Board of Health and Welfare.

As regards the conversion of LASS costs into set prices, we have used the SCB (Central Bureau of Statistics) Consumption Index for Care of the Elderly and the Disabled, which is the one used by the National Board of Health and Welfare in their report on welfare services for the disabled. The index is described in appendix four.

As Sweden does not register any citizen's functional impairments, there is no information on average lifespan and mortality for people with extensive functional impairments. As there are no longitudinal investigations in the field, it is not possible to study the flow of people between different support measures or trace changes to life conditions and use of measures. However, the National Board on Health and Welfare has carried out some minor studies, for instance in connection with the follow-up of the disability reform.

In order to further highlight certain issues we have used preliminary results from two field surveys of members of the JAG Association carried out in 1995 and 2005, respectively.

Chapter four – Conclusion

In the final chapter, we present our general conclusions.

2. COST COMPARISON BETWEEN PERSONAL ASSISTANCE AND ALTERNATIVE SUPPORT MEASURES

Is personal assistance more expensive than other support measures? This chapter examines the cost per person in a number of group homes and compares it to that of personal assistance. In distinction to other comparisons made, we look at the actual extent of the support for a number of individuals. The result is unequivocal: in several of the examined cases, personal assistance is cheaper and also more flexible than other forms of support and service.

This section focuses on comparing personal assistance to group homes. For people with several extensive functional impairments, one of which is an impairment of intellectual ability, it is most common to assign support measures in the form of personal assistance or some type of group housing. Home-help service or other sporadic measures are only really a viable option for people who have less extensive needs and/or receive basic support from family members in the household. It should be mentioned that in a project by the Association of Local Authorities, the cost of producing one hour of home-help service was estimated at SEK 300–400.⁶ Thus, one hour of home-help service far exceeds the cost of one hour of personal assistance, in spite of the fact that home-help service provide for less qualified support needs.

The National Audit Office in their 2004 report wrote that

”For economic reasons, the municipality can refrain from building group homes. In 2001, a place in residential arrangements with special service cost an average of SEK 556,000 per year. The municipality contributes the entire cost. The same year, personal assistance with state assistance benefits cost the municipality a third of this amount (SEK 192,000 per year and user). The publicly funded total cost of personal assistance was SEK 860,000 that same year. This means that personal assistance is a significantly less expensive support measure for the municipality than a place in residential arrangements with special service, in spite of the fact that personal assistance is a more expensive measure for society as a whole.”

The National Audit Office argues that the municipalities benefit from transferring service from group homes to personal assistance, that the cost of personal assistance is higher than that of group homes and that the financial incentives consequently work ”in the wrong direction”. This statement from the National Audit Office is sweeping and quite serious and we will show in this chapter that it is also unfounded. It is misleading to compare the average cost for all the residential arrangements with special service to the average cost of personal assistance. A correct comparison strongly indicates that the opposite holds true: group homes are more expensive than personal assistance for the users in question.

We will start by analysing what the average cost stated by the National Audit Office, SEK 860,000, really means. The average hourly cost of personal assistance that year was SEK 184.83. That means the average user of personal assistance, according to the National Audit Office, was a person who receives close to 90 assistance hours per week.⁸ The question is if the average user of ”residential arrangements with special service” receives the same level of service, i.e. 90 hours per week? We looked at the issue by studying the two categories of service housing.

The first category of group homes is for people who have a need for basic daily assistance with care, hygiene, communication, eating, washing, etc. Those homes are often designed to have small simple apartments that connect to a shared common area. The other category consists of service homes where people who primarily need motivational and advice measures live in separate

⁶ National Association of Local Authorities, 2003

⁷ National Audit Office 2004, p. 87

⁸ 860 000/184,83/52 (weeks)

COST COMPARISON BETWEEN PERSONAL ASSISTANCE AND ALTERNATIVE SUPPORT MEASURES

	Nationally	Uppsala	Eskilstuna	Skellefteå	Stockholm
Special housing according to LSS, average annual cost per person, SEK thousand	625	534	622	495	857

Table 1: Average cost per person in special housing according to LSS 2003, SEK thousand.

Source: National Board on Health and Welfare, 2004c

complete apartments with access to staff and a common area in the vicinity. Both categories are considered residential arrangements with special service according to LSS.⁹

It is reasonable to assume that few of the people who only need the less extensive support in the second category, service homes, would be eligible for personal assistance according to LASS, as they do not have any need of support for their basic needs, which is a condition for the latter measure. The housing category that dominate the supply varies between municipalities, and thus also the people who are offered the respective alternatives. There is no statistics on how many people live in each respective type of homes. The statistics only list people in residential arrangements with special service. In the light of the above, it is unreasonable to assume that the average cost for people in residential arrangements with special service could be directly compared to the average cost of personal assistance. It also indicates that the statement by the National Audit Office is less than well founded. A more in-depth analysis of the actual conditions reinforces this impression.

For the continued analysis, we have compared the cost of group homes for people who have extensive needs for support and service to the cost of personal assistance according to LASS. We have examined the amount of support provided to the users on the basis of the staffing of the group homes and how much those measures cost. The result we get is the number of potential personal assistance hours that correspond to the cost of group homes.

The group homes that we studied are located in Uppsala, Eskilstuna and Skellefteå. We also studied the City of Stockholm, where they have implemented a system of individual lump-sum compensations for the costs of

group homes. There, there is no reason to do a detailed review of separate group homes, but instead use the support needs levels that the lump-sum compensation is based on. The results are presented in two separate sections.

The costs in sections 2.1 and 2.2 refer to 2004. How the costs of special housing according to LSS in the studied municipalities relate to the national average 2003 is apparent from table 1.

2.1 A cost comparison between personal assistance and group homes in Eskilstuna, Uppsala and Skellefteå

Comparison basis

Below, we present the residential arrangements whose costs we have reviewed. They are all LSS homes and they specifically target people with extensive functional impairments where one of the impairments is intellectual. The people living in the group homes are in need of continuous support during 90–100 hours per week (the average number of granted assistance hours has grown to a present level of 100 hours per week). Thus, they are comparable to personal assistance.

The municipalities' cost for the service in the group homes is presented per day. By multiplying the daily cost by the number of days per week, we get the weekly cost. In connection with the presentation of each group home, we present the number of weekly hours of personal assistance that the cost corresponds to, according to the average hourly cost of personal assistance presented by LASS for the same year, which is SEK 206.7.¹⁰ Naturally, the comparison is schematic but it still provides an impression of the costs in relation to each other.

⁹ Swedish Association of Local Authorities, 2004 and National Board of Health and Welfare, 2003e

¹⁰ Olof Widmark, The Swedish Social Insurance Agency, 2005

People that are eligible for personal assistance when they are awake often also have someone on call at night.

On call means that a personal assistant who will provide active measures if needed, is at hand or else sleeping. The actual work is performed if needed and not on specific times, which means that the assistance is at hand the entire night. The Swedish Social Insurance Agency pays compensation for 15 minutes per hour for this. Consequently, when calculating the number of assistance hours provided at the same cost as for the daily cost of group homes, we include a number of night hours that cost less per hour. The number of night hours in our comparisons is the same as the "night staff" for each group home. The most common number of on-call hours for personal assistance is eight hours per day. Here, we have chosen to use the conditions in each group home as a basis in order to facilitate comparison.

There are also instances where people are granted personal assistance for the night, and where the assistants remain awake throughout. For those people, a group home with normal staffing, is not an option. The municipality would then be forced to employ additional staff at a far higher cost. Therefore, group homes that have this need often have special compensation, in Stockholm for instance, this is negotiated on an individual basis.

In order to be able to do a schematic comparison, we have divided the support provided by personal assistance or group home staff into three time categories:

Individual staff time is when an employee continuously provides support to one single user, when the time is reserved for this user alone and nobody else can avail of the employee's services.

General staff time is the user's share of the available staff on the condition that the residents in the group home share the staff resources equally.

Other manned time is time during which no service is provided. For example, when the group home staff

is providing service to another user, but can be called upon. For personal assistance, this corresponds to the on-call time that is not active.

In addition, we present *time regularly spent in daily activities* when support is provided by the daily activities staff and the cost of the support is not borne by the group home/assistance benefit. Of course, it is probable that the users in the group home also spend time outside of the home, where they might receive support from others than the staff of the home itself, but we have no information about this and cannot include it in our example.

Likewise, the staff in the group home performs important tasks even when the users are not in the home, but spends time in, for example, daily activities. It concerns administration, staff meetings, instruction, contact with user representatives, etc. This also applies to personal assistance; in addition to the hours granted by The Swedish Social Insurance Agency, personal assistants participate in training, meetings, instruction, etc. The Swedish Social Insurance Agency grants no additional funds for this, all the salaries and other costs are covered by the benefit paid for the granted assistance hours. In order to make the comparison as fair as possible, we have chosen not to count those hours as support hours, neither for group home staff nor for personal assistants.

Consequently, the assistance benefit is intended to cover the entire cost of the service as well as the attendant costs. The budgets of the group homes may differ somewhat as regards what kind of costs are covered. Instruction and central administration are part of the budget for homes of case 1. For case 2 and 3 it is covered by a lump-sum addition of seven percent in the municipalities' accounts. For case 4, the municipality adds ten percent for overheads when selling places to other municipalities and organisations. As is apparent below, we have taken those additions into consideration when doing the comparison. The rent of each user is considered revenue, and is thus not part of the costs.

COST COMPARISON BETWEEN PERSONAL ASSISTANCE AND ALTERNATIVE SUPPORT MEASURES

Case 1

Case 1 targets people with multiple impairments who have "very extensive support needs". Five people live in the group home.

Extent of support in the group home

From 7 am to 9 pm, there are three employees in the group home. From 9 pm to 7.15 or 8.15 am, there is one employee on duty. Four of the users have daily activities between 9 am and 3 or 3.30 pm. One person has daily activities during one day a week. On average, each user spends 25.5 hours per week in daily activities outside of the home. For four days a week, approximately six hours per day, there are three employees available to the one person who does not attend daily activities. On the fifth day, the three employees are by themselves for six hours. This is one part of the explanation for the high cost of service for group homes. We estimated general staff time to 57 hours and other time to 85 hours per user.¹¹

Cost of support in the group home

The cost per person is SEK 21,609 per week.

How much personal assistance does the same amount of money buy?

On the condition that the people would spend the same amount of time in daily activities, i.e. 25.5 hours, there are 142.5 hours remaining in the week. SEK 21,609 would cover personal assistance for 157¹² hours, including on-call hours at night.

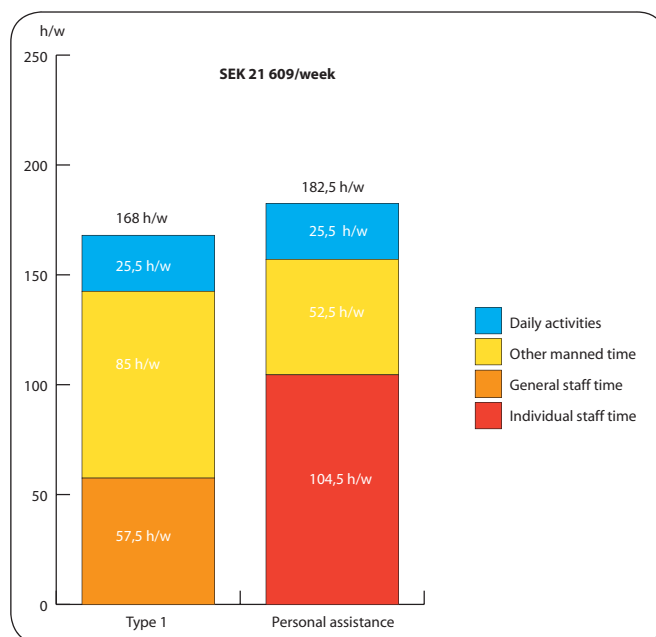


Chart 1: Comparison between case 1 and personal assistance

¹¹ General staff time and other manned time respectively, have been calculating as follows: The daily staff time is 14 hour per day, 7 days a week= 98 hours. We deduct the 25.5 hours when the users are in daily activities. What remains is 72.5 hours x 3 employees = 217,5. We add 7 nights with one employee, 70 hours (217,5+70=287,5). This is shared between the 5 users = 57,5 general staff hours each. The remainder, 85 hours, consists of other manned time.

¹² The number of assistance hours for the same amount equals 104.5 (21,609/2067=104,5). The ten on-call hours per night cost 25% of the hourly rate. First, we deduct the cost of the 70 on-call hours during the week, which amount to 17.5 hours (25% of 70) Then we add the on-call hours (104,5-17,5+70 =157).

COST COMPARISON BETWEEN PERSONAL ASSISTANCE AND ALTERNATIVE SUPPORT MEASURES

Case 2

Case 2 targets people diagnosed with autism and extensive support needs. Four people live in the group home.

Extent of support in the group home

In this group home, the staff must also meet the users' need for daily activities. The users have access to the staff 168 hours per week. From 7.30 am to 9.30 pm, there are four people on duty at all times. At night, the four users share one employee. We have estimated individual staff time to 98 hours, general staff time to 17.5 hours and other manned time to 52.5 hours per user.¹³

Cost of support in the group home

The weekly cost is SEK 25,312. For central administration, there is a lump-sum addition of seven percent. Thus, the total cost amounts to SEK 27,084.

How much personal assistance does the same amount of money buy?

27,084 covers 183.5¹⁴ hours of personal assistance, including nightly on-call hours, compared to 168 hours in the group home.

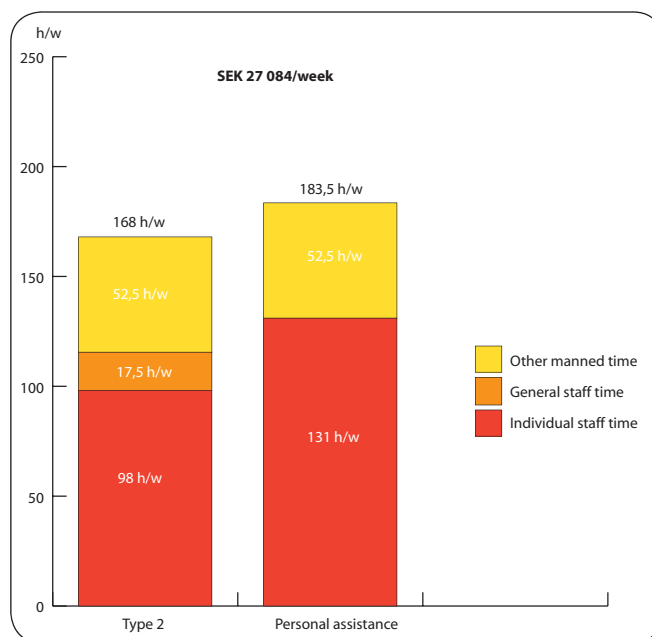


Chart 2: Comparison between case 2 and personal assistance

¹³As there is one employee per user during 14 hours per day, we assume that amounts to 7 days x 14 hours of individual staff time without waiting periods for the users = 98 hours. General staff time and other manned time has been estimated at 10 hours per night as per below: 7 nights with one employee, a total of 70 hours, is shared between four users = 17.5 general staff time per user. The remainder, 52.5 hours, consists of other manned time.

¹⁴The number of assistance hours for the same amount equals 131 (27,084/206.7=131). The ten on-call hours per night cost 25% of the hourly rate. First, we deduct the cost of the 70 on-call hours during the week, which amount to 17.5 hours (25% of 70) Then we add the on-call hours. 131-17.5+70=183.5

COST COMPARISON BETWEEN PERSONAL ASSISTANCE AND ALTERNATIVE SUPPORT MEASURES

Case 3

In case 3, there are four people with intellectual impairments living in the group home.

Extent of support in the group home

The number of staff varies during the day, from three people between 7 am and 4 pm and two people until 9 pm. At night, one person is working. The users spend an average of 30 hours outside of the group home, in daily activities etc., where other staff provides support and service. That leaves 138 hours for which the staff in the group home is responsible. We estimated general staff time to 59.75 hours and other time to 78.25 hours per user.¹⁵

Cost of support in the group home

The weekly budget is SEK 17,332. The lump-sum supplement for central administration is seven percent, which gives a weekly total of SEK 18,545.

How much personal assistance does the same amount of money buy?

Some of the support and service to the users is provided by, for example, the daily activities staff. That leaves a remainder of 138 hours per week. SEK 18,545 would suffice for 142.2¹⁶ hours a week, including nightly on-call time.

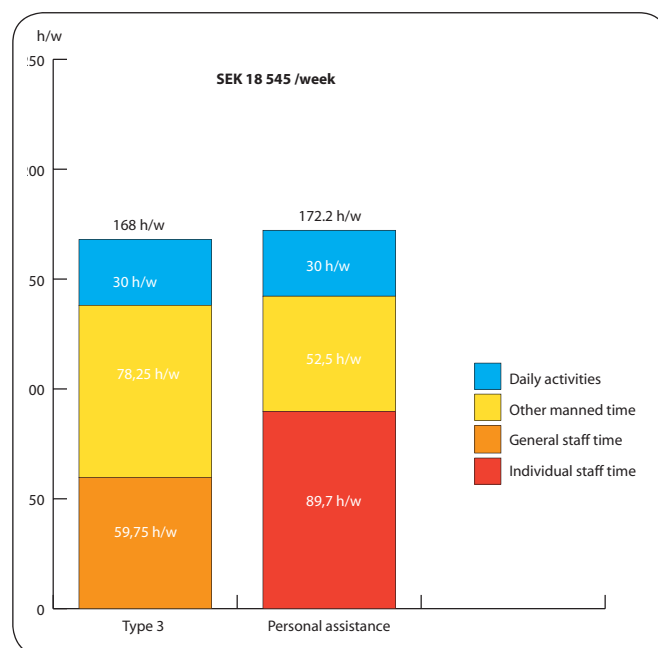


Chart 4: Comparison between case 4 and personal assistance

¹⁵ General staff time and other manned time respectively, have been calculating as follows: The daily staff time is 9 hours per day, 7 days a week= 63 hours. We deduct the 30 hours when the users are in daily activities. The remainder is 33 hours x 3 employees = 99. The afternoons and evenings consist of 5 hours, seven days a week = 35 hours. Two employees work during this time = 70 hours. We add 7 nights of 10 hours each with one employee, 70 hours. 99+70+70=239. This is shared between the four users = 59.75 general staff hours each. The remainder, 78.25 hours, consists of other manned time.

¹⁶ The number of assistance hours for the same amount equals 89.7 (18.545/206,7=89,7). The ten on-call hours per night cost 25% of the hourly rate. First, we deduct the cost of the 70 on-call hours during the week, which amount to 17.5 hours (25% of 70) Then we add the on-call hours. 89,7-17,5+70 =142,2

COST COMPARISON BETWEEN PERSONAL ASSISTANCE AND ALTERNATIVE SUPPORT MEASURES

Case 4

There are four people with intellectual impairments living here.

Extent of support in the group home

The number of staff varies during the day. From 6.30 am to 1.30 pm, there are three employees working; then there are four people working for 30 minutes and then three people again until 3.30 pm. Until 10 pm, the staff consists of two employees. At night, the staff consists of one person on duty and one on call. The reason for having an extra staff member on call during the night is that the home provides service to a fifth user, who lives in a separate service home. If the member on duty needs to go to the service home, the member on call is available in the group home. In practice, that means that the four users in the group home have access to one staff member at night. Two of the users attend daily activities for four hours every weekday. On average, they spend 158 hours per week in the home and only receive service in other ways for ten hours. We estimated general staff time to 67 hours and other time to 91 hours per user.¹⁷

Cost of support in the group home

In case 4, the weekly budget is SEK 19,383 for a place in the home. With the ten-percent lump-sum contribution for central administration, the total cost is SEK 21,321.

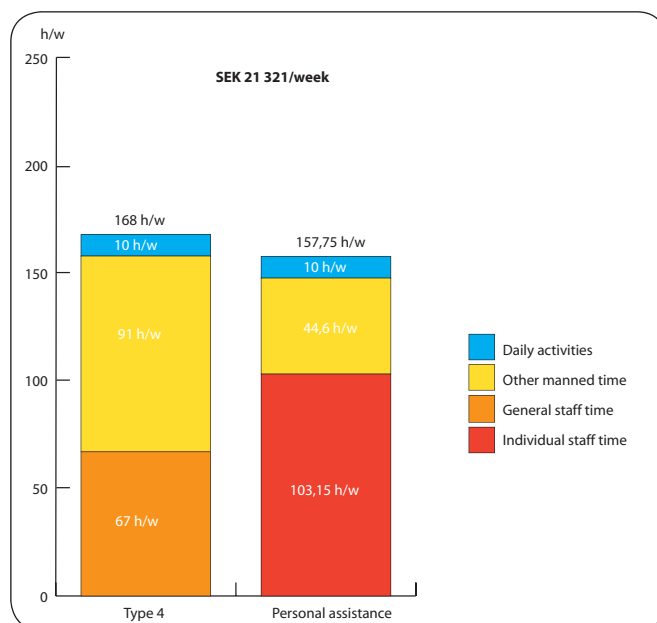


Chart 4: Comparison between case 4 and personal assistance

How much personal assistance does the same amount of money buy?

The group home provides support to the users for an average of 158 hours per week. SEK 21,321 covers 147.75¹⁸ hours of personal assistance, including sleeping on-call duty for 8.5 hours a night.

¹⁷ General staff time and other manned time respectively, have been calculated as follows: The daily staff time is 8.5 hours per day, 7 days a week = 59.5 hours. We deduct the 10 hours when the users are in daily activities. The remainder is 49.5 hours x 3 employees = 148.5. For 0.5 hours per day, the staff consists of four people, 3.5x4 = 14. Afternoon and evenings amount to 6.5 hours, seven days a week = 45.5 hours. Two employees work during this time = 91 hours. We add 7 nights of 8.5 hours each with one employee (ignoring the on-call member that we count as support for the fifth user in the separate apartment), 59.5 hours. 148.5+14+45.5+59.5=267.5. This is shared between the four users = 66.9 general staff hours each. The remainder, 91 hours, consists of other manned time.

¹⁸ The number of assistance hours for the same amount equals 103.15 (21,321/206.7=103.15). The 8.5 on-call hours per night cost 25% of the hourly rate. First, we deduct the cost of the 59.5 on-call hours during the week, which amount to 14.9 hours (25% of 59.5) Then we add the on-call hours. 103.15-14.9+59.5=147.75

We would like to point out that the estimates above are only a method for comparing the support measures. Naturally, we know nothing about the number of personal assistance hours those people would be granted if they applied for it. It is worth mentioning that the average number of granted assistance hours in 2004 was 98.7 hours per week. Only in case 3 would the cost of service in the group home not cover the corresponding number of assistance hours.

2.2 A cost comparison between personal assistance and group homes in Stockholm

Starting points

Since 1999, Stockholm keeps statistics of the costs of care for the disabled, divided into different activities. In 2003, Stockholm's average cost for special housing according to LSS amounted to SEK 857,000 per group home place, compared to the national average of SEK 625,000 (see table 1).

In Stockholm, the responsibility for measures targeting people with functional impairments rests with the municipal district boards. Instead of studying different group homes, we used Stockholm's benefit levels for people with various support needs in 2004²¹ (see chart 5). The support need is defined as the number of hours of directed support to each resident, i.e. the number of hours that the staff is estimated to spend individually

on each person (cf. individual staff time) in the group home. According to the municipality officials, the agreement between benefit level and final cost in the system is good.²²

At level 16, the costs are calculated after an individual assessment of the need. We also compared this level to personal assistance, but on the basis of examples from one of Stockholm's district councils. That comparison can be found at the end of this section.

Support needs according to levels 11–15

The pink columns in chart 5 illustrate how many assistance hours each benefit level could finance. For levels 14 and 15 we present the assistance hours including eight hours of sleeping on-call duty, as the extent of the support means that the home cannot be left unmanned at night.

As regards levels 11–13, it would seem that personal assistance at the average hourly cost in 2004, SEK 206.70, could be granted at a greater extent than the number of hours corresponding to the needs, as the potential assistance hours exceed the number of hours that constitute the upper limit for the equivalent level. Level 14 however, is the first level that could be considered equivalent of the need for basic personal support and care for at least 20 hours per week, which is a condition for being granted assistance benefit according to LASS. That means that comparing personal assistance to spe-

²¹ The support needs per level are defined in Stockholm's Instruction for assessing support level according to the following:

"Support level [11] comprises support for people who are independent and often living in an "external apartment". [...] The staff primarily provides oral instructions, reminders, assistance in daily planning and support to the resident in developing greater independence."

"In addition to what is covered in level 11, level 12 comprises the following: The staff assists in initiating different activities like domestic activities and also provides oral instructions, encouragement and some help. The staff is not necessary during the entire time an activity is ongoing, but can leave for short periods when the resident has become fully involved. More extensive support in daily planning than at level 11, for example remembering the time, getting to planned activities, and some initial support during leisure activities. Being there when the resident contacts you for help."

"Level 13 comprises support measures according to level 12 as well as more oral support, recurring instructions and practical assistance during certain parts of domestic work and other activities."

"Level 14 comprises support measures according to level 13 as well as support with showering, dressing, meal assistance, etc. Possibly also help with interpreting alternative means of communication or supervision due to epileptic fits or similar conditions."

"Level 15 comprises all measures covered by level 14, and also requires the staff to support the resident during all of his or her waking hours. In certain instances, for example when moving, support of two staff members may be required. The support includes comprehensive practical, and/or social and mental support."

"Level 16 applies to a small number of individuals who need to be in constant contact with staff and require comprehensive practical and/or social and mental support. Staff members never work alone with the resident."

²² Snorre Berglund, City of Stockholm.

COST COMPARISON BETWEEN PERSONAL ASSISTANCE AND ALTERNATIVE SUPPORT MEASURES

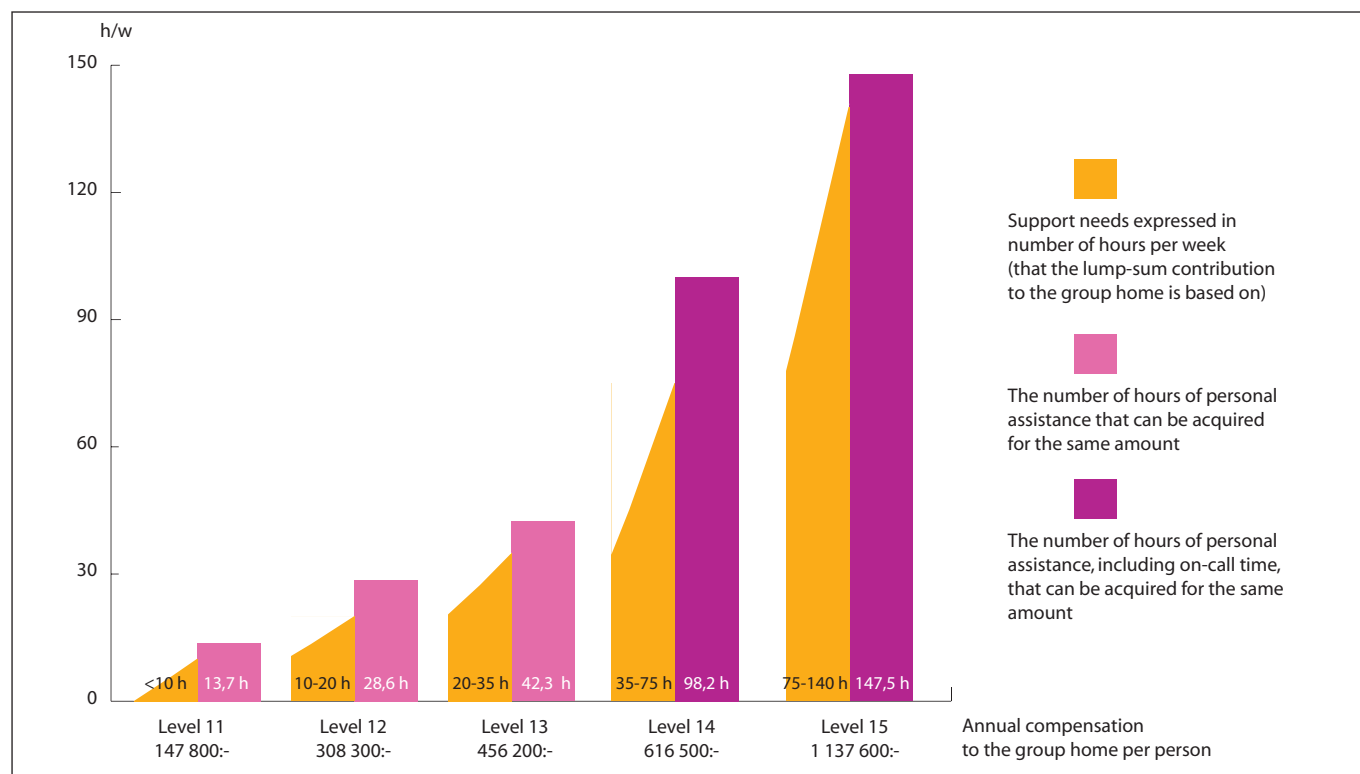


Chart 5. Comparison between the benefits for group homes in Stockholm in 2004 for different support needs and personal assistance. In 2004, the average cost of personal assistance according to LASS is SEK 206.70 per hour. Sources: City of Stockholm, 2001.

cial residential arrangements for level 11–13 hardly applies to LASS, but rather to personal assistance funded by the municipality according to LSS.

For levels 14 and 15, personal assistance covers far more than the need expected to be met by the group home at the same cost. The benefit for level 15 covers personal assistance round the clock, assuming that the user participates in daily activities for twenty hours a week and has on-call assistance at night.

Support needs according to level 16

During talks to a controller in one of Stockholm's town district committees, it became apparent that three people in the district had been assessed to be in need of level 16. This information was confirmed by the unit manager, who added that two out of the three users needed access to continuous personal support. We chose not to reveal the district in question, as people could easily be identified.

Person 1 does not really need continuous support, but as the others in the group home live in satellite apartments, it is not possible to assess this person's needs in relation to those, without granting support according to level 16. He does not participate in daily activities.

Person 2 lives in a traditional group home, but must have access to one dedicated carer at all times. At night, there are two people awake in the group home, as he needs constant access to help and support. Otherwise, there would only be one employee present at night.

Person 3 has very extensive needs. He lives in a satellite apartment and has one staff member with him at all times. All lifts require two staff members. The man also has full-time daily activities, which means that the activity is manned for him to attend between 9 am and 4 pm every day. However, he does not always want or is able to participate. In those instances, his support needs must be met by the staff in the group home. At night, there is one staff member awake in the apartment.

For the support of those people, within the framework of residential arrangements with special service, the municipality allegedly pays around SEK 31,000–32,000 per person and week. It would be sufficient for 150–155 hours of personal assistance per week, with assistance awake throughout the night. None of the three users seems to have continuous individual support in the home at all hours, but instead shares the support with others, or participates in daily limited activities. Therefore, it seems reasonable to assume that it would not be more expensive to meet their needs through personal assistance. Conversely, the examples highlight the difficulties and expenses caused by meeting people's needs within the framework of residential arrangements with special service.

2.3 Discussion

This chapter shows that the reasoning from i.a. the National Audit Office about limiting the target group for personal assistance, on the basis of the argument that group homes are less expensive, is based on a far too shallow analysis. The average cost of personal assistance cannot be directly compared to the average cost of a place in residential arrangements with special service, as the average need and extent of the measures are fundamentally different. In many instances, the comparison is even incorrect as the cost for a place in a group home often ignores the overheads in the form of administration, etc. that the municipality pays. The municipalities' costs for planning and building group homes are not included in the costing either.

In no material have we found calculations to show that group homes generally are more cost-effective than personal assistance. Neither is it possible to find evidence of there being too few group homes in the municipalities – but there are apparently individuals who feel that it is difficult to find a suitable group home, on the basis of location, composition of the group, method, etc.

The fact that state-funding of personal assistance leads to the municipalities failing to fulfil their obligation to provide sufficient group homes, is one of the main arguments in the National Audit Office report. With that, they ignore the difficulties linked to this, which

are described in the report *Planning housing for people with functional impairments*.

The report is the result of a project where 20 municipalities were mapped in order to support the municipalities in the planning and building of housing for people who, for various reasons, are in need of special support. In it, representatives of municipalities and users alike express that the future housing for people with functional impairments will be more individualised than is the case today. The present group homes do not meet the existing needs, but regulations and subsidies cement the traditional collective forms of housing, primarily for people with intellectual impairments. It is not unusual for municipalities to have vacancies in several different group homes that do not suit any person requesting the support. Everything, from personal chemistry with other residents to the design of the home and the skill of the staff is important when matching a certain home with a certain individual.²³

In spite of the fact that the need, according to the report by the Swedish Association of Local Authorities, rather seems to be for a more diverse supply of housing for people with functional impairments, there is instead a clear risk that more group homes are being built. This risk becomes more imminent because of incorrect cost comparisons.

In this chapter, we have shown that a place in a group home for someone with extensive needs costs as much as providing personal assistance for the greater part of the day. In the Stockholm example and in three out of four group homes presented, personal assistance is more cost-effective. This is very well worth noting, particularly as there is a marked difference in support quality. The staffing of the group homes is not tailored to provide continuous individual support, but is instead based on the users either managing independently for some of the time or being able to "wait their turn" if everyone on the staff is busy.

It should also be noted that residential arrangements with special service do not constitute round-the-clock support. Many people in group homes spend time outside of the home, for example when visiting family and friends. In those instances, the staff in the group home rarely attends, but instead usually grant temporary

²³ Swedish Association of Local Authorities, 2004

support measures for each occasion, which entails an additional cost. For many, this does not actually happen, instead those visits are solved by having a relative providing the necessary support, often unsalaried.

It is also common for people in group homes to use LSS measures, such as personal contact and companion service.²⁴ A reason for this is that the staff in the group homes generally numbers fewer than the residents, and if one of them were to accompany one of the residents to a leisure-time activity, the remaining staff would be short-handed.

One consequence, often overlooked, of the fact that the group homes "share" one employee at night, is that the users are never able to spend the night outside of the group home. The on-call assistant however, always accompanies the user, irrespective of where he or she goes. Naturally, this entails a huge difference to the individual's flexibility and freedom.

Another difference between personal assistance and group homes is that, for many group homes, a large part of the staff's working hours is scheduled during times when there is nobody in the home. Meanwhile, the users receive support from staff in other activities, for example daily activities. The reverse occurs when one of the residents of the group home is ill and cannot participate in the daily activities. Then the daily activities

are left with only a few or no users, while the staff in the group home provides the support.

The opportunities for flexibility and self-determination when using personal assistance are obvious. Often, this difference in quality compared to collective support forms is presented as more costly, and that the issue of which support should be offered is a financial consideration about how generous society should be. Our inquiry has shown that, from a financial perspective, one could equally well offer personal assistance as group homes, if it concerns an individual with extensive support needs.

Through the individual needs assessment of personal assistance, the staff resources are always allocated to those who are in need of them. As the cost of a place in a group home is determined on the basis of collective needs, the individual needs assessment is done by the group home staff, which leads to greater uncertainty and less legal security for the individual.

On the whole, our comparisons in chapter two have shown that there is no evidence in favour of group homes being less expensive than personal assistance. Our conclusion is that there are very few opportunities for saving money by limiting the possibility of granting personal assistance to people with extensive functional impairments and impaired intellectual ability.

²⁴ National Board of Health and Welfare, 2004a

3. REVIEWING MEASURES AND COSTS

The number of people who have been granted support measures according to LSS, SoL and HSL has increased significantly since the beginning of the nineties. In set prices, the average cost per user eligible for assistance has been more or less constant over the last few years. The hourly cost is even less today than in 1994. The statistics show that the average age is growing and that the largest group of users today is the 62–66 year-olds. The assistance reform turned out to be more expensive than expected as both the number and the needs of the people eligible were underestimated. This is to a great extent due to the fact that nobody had counted on the measures previously provided by relatives for very little or no remuneration, which is confirmed by a survey among JAG members.

It has been almost twelve years since LSS and the assistance reform were implemented. Initially, the reform entailed greater costs than predicted and the costs are still rising, primarily those of state funded personal assistance. This may seem surprising. The right to assistance benefits according to LASS applies to people who have such extensive service needs that they should be in close contact with various authorities and thus be familiar with the various measures on offer. Therefore, they should have been in the system from the beginning. It could be argued that those who are now eligible for personal assistance should not cause the group to grow, but rather that they replace those who pass away or for other reasons no longer use personal assistance. Through the system of lump-sum assistance benefit, the state has more or less full control over the cost per hour. The majority of municipalities use the same lump-sum amount for the assistance they are funding. The fact that the cost of personal assistance still increases is often presented as an enigma.

Several authorities, among others the Swedish Social Insurance Agency and the National Board of Health and Welfare, have tried to find solutions through their own inquiries. Unfortunately, there are no inquiries mapping the actual use; instead, the majority of the inquiries are based on field surveys among LSS or LASS administrators.

The results in this chapter are based on both our own inquiries and on information from relevant published statistics in the field.

The system of assistance benefits according to LASS is designed to keep the Swedish Social Insurance Agency updated about precisely how many people receive the

support, how many hours they use and at what cost. There is no corresponding information for individuals at the National Board of Health and Welfare for LSS measures. That is why we have studied the statistics on LSS, LASS and other forms of support for people with functional impairments from two different perspectives.

First, we reviewed the development for the number of people on different support measures (section 3.1). The purpose is to make a general study to see if any support measures have dropped in popularity while the use of personal assistance has increased.

We also studied the statistics on cost development in both LSS and SoL in order, when the data allows it, to see if the cost of personal assistance is in line with the cost development for general support and service for people with functional impairments, or if it is significantly different (section 3.2). In the light of that, in section 3.3 we review what happened during the initial stages of the reform. In section 3.4 there is a brief presentation of two field surveys of assistance users, carried out in 1995 and 2005 respectively. In section 3.5 we look at the future cost trends.

3.1 The progress of people receiving support measures

When the assistance reform was implemented, the intentions were to replace some existing and sometimes flawed measures in, for example, home care, home service and group homes, but that all those measures should be continually on offer at the same time as

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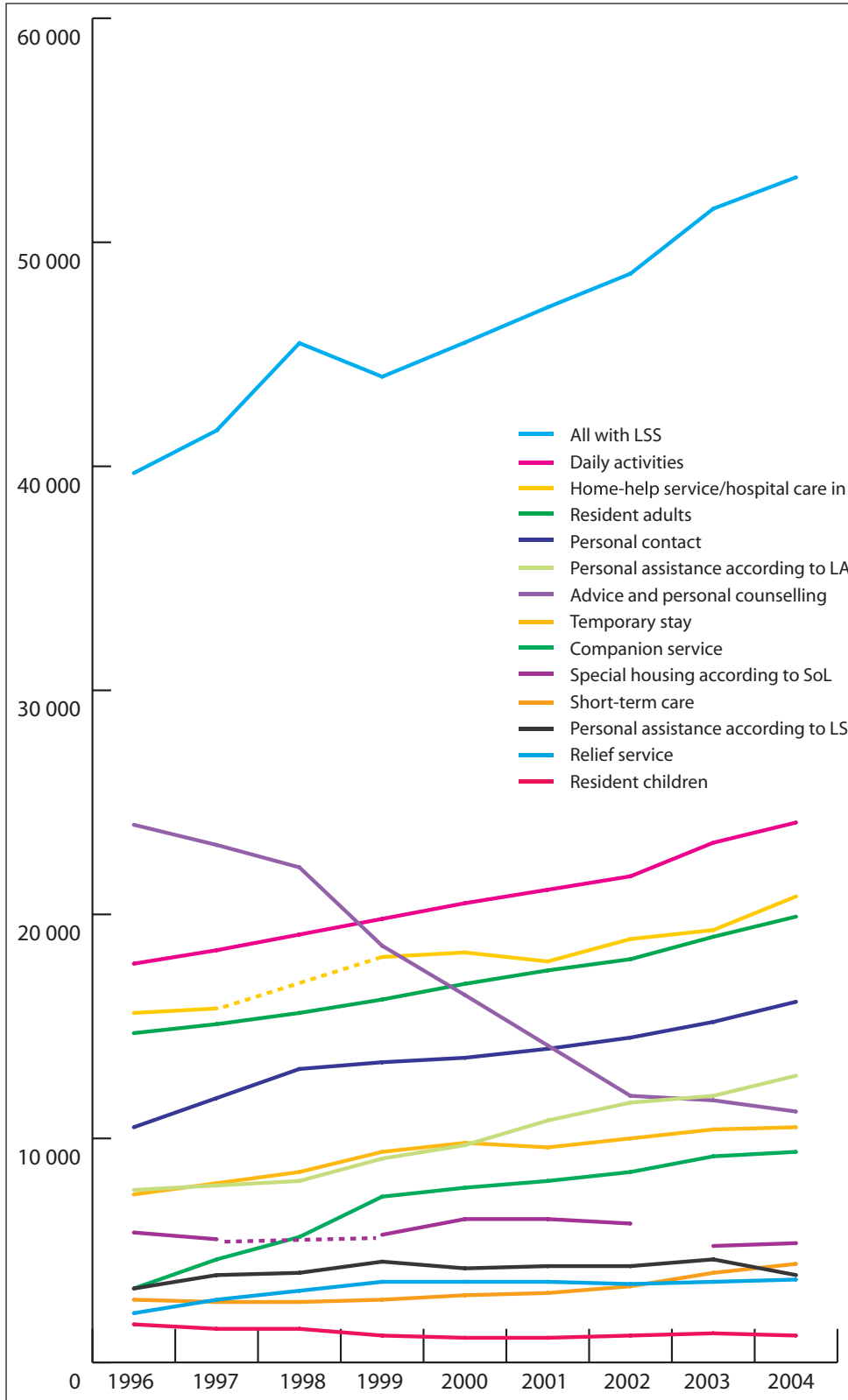


Chart 6: The number of people with support measures according to LASS, LSS, SoL and HSL 1996–2004. The number of people in "all with LSS" are fewer than the sum of individual measures, as one person can be the recipient of several measures. The chart starts in 1996 as there are no national statistics on support measures according to LSS before 1996. The number of people "all with LSS" according to the chart do not include people with only personal support and counselling. There is no data for 2001 on the number of people with counselling and personal support due to a loss of statistics that year. It also appears as if the number of people with personal assistance according to LSS fell between 2003 and 2004 but that is not the case. When gathering the data for 2004 the National Board of Health and Welfare sent a letter to the Swedish municipalities clarifying the people with personal assistance that should be reported in the statistics, which led to extensive amendments and making comparison with previous years impossible. In 1998 there were no data on homecare/hospital care in the home and special housing according to SoL. In 2002–03 there is a gap in the graph for special housing according to SoL. That is due to the fact that the data before 2003 also include temporary residents. 2003 and later include only permanent residents. Sources: The National Board of Health and Welfare, 1996, The National Board of Health and Welfare, 1997b, The National Board of Health and Welfare, 1999, The National Board of Health and Welfare, 2000a, The National Board of Health and Welfare, 2001a, The National Board of Health and Welfare, 2002a, The National Board of Health and Welfare, 2003a, The National Board of Health and Welfare, 2004a, The National Board of Health and Welfare 2005a, The National Board of Health and Welfare 2005b and the Swedish Social Insurance Agency statistics on assistance benefits

REVIEWING MEASURES AND COSTS

	1992	1996	2000	2004
Nursing home	3 600	1 300	–	–
Group home and boarding house according to the Social Welfare Act (1992) as well as residential arrangements with special service according to LSS for children and adults (1996-2004)	11 300	16 400	18 100	21 100
Total	14 900	17 700	18 100	21 100

Table 3: The number of people in special housing in 1992 and 1996. In 1992 there were a total of 29,180 people receiving special care according to the Social Welfare Act that, like LSS, included additional measures.

Sources: the National Board of Health and Welfare, 1993 the National Board of Health and Welfare, 1997b.

personal assistance, as the assistance would be for those with the greatest need for an individually tailored service. Thus, the objective of the reform was to replace parts of those measures, but far from all of them.

A summary of available statistics on the most common support measures for people with functional impairments does provide a clear illustration of a steadily growing group of people who are granted due to one or several functional impairments. In 1996, a total of 39,694 people were granted support measures according to LSS, in 2004 the number had grown to 52,900. During the first year of the reform, in 1994, a total of 6,383 people received assistance benefit according to LASS. In 2004 the number had grown to 12,751.²⁵ Chart 6 illustrates how the number of users of various support measures for people with functional impairments changes between 1996 and 2004 (see appendix 2).

The utilisation of more or less all LSS measures increased during the period from 1996–2004. It is obvious that the growing number of people being granted personal assistance is part of a general increase in the number of measures for people with functional impairments. Residential arrangement with special needs for adults is also growing at approximately the same pace as personal assistance. Thus, statistics do not support the notion that personal assistance replaced service in group homes during the period. The number of people below 64 years of age who were permanently or temporarily staying in special housing according to SoL also grew during the period, in connection with LSS and LASS being introduced.

Only personal advice and counselling, as well as the number of children in special housing according to LSS, saw a decrease. The fact that the number of children in special housing decreased is probably a direct result of the improved quality of support for families with children who have functional impairments, not least the possibility of acquiring personal assistance for children. The decreasing instances of advice and personal counselling is mostly due to the decision by the Supreme Administrative Court in 1997, that certain rehabilitation measures do not fall under advice and personal counselling.²⁶

Aside from the developments over the past few years, we also studied statistics from the period around the reform as well as the preceding years in order to see if previous support measures have been replaced by personal assistance. For people with intellectual impairments, the measures were regulated in the Social Welfare Act (1985:568) from 1986 to 1994. As is apparent from table 3, in 1992, a total of 14,900 people in nursing homes, group homes and boarding houses according to the Social Welfare Act (of which just under 10,000 lived in group homes and 1,330 in boarding houses).²⁷ In 1996, the number of people in corresponding housing had risen to 17,700. Only 604 people of those who, in 1996, lived in residential arrangements with special service according to LSS, belonged to client category 3 – the category not previously covered by the Social Welfare Act. This share is increasing steadily until 2003, after which LSS measures are no longer presented per client category (see appendix 2).

²⁵ The Swedish Social Insurance Agency

²⁶ Norström, C & Thunved, A, 2005 p. 393

²⁷ The National Board of Health and Welfare, 1993

REVIEWING MEASURES AND COSTS

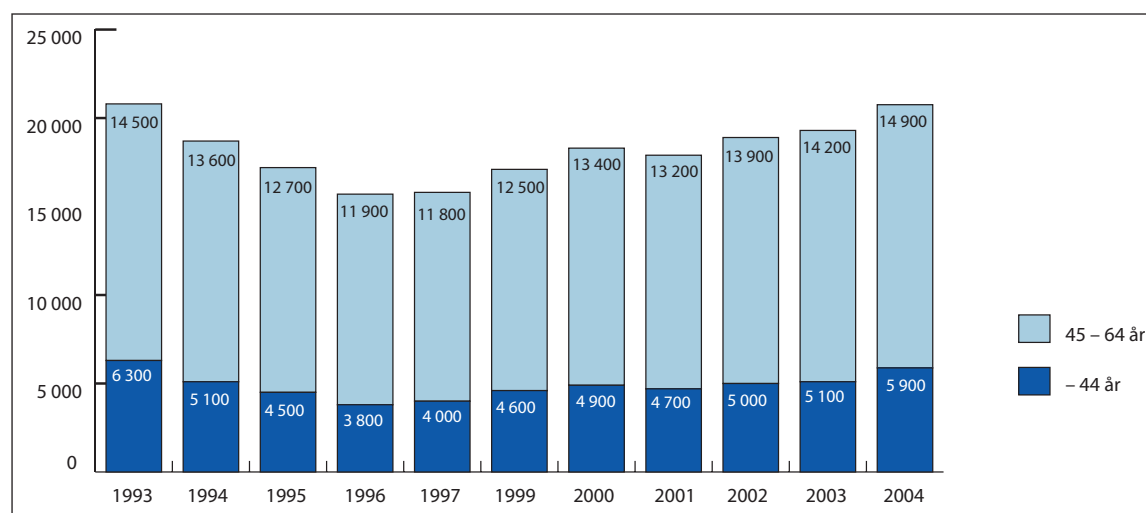


Chart 7: The number of people between ages 0 and 64 with home-help service and/or healthcare in their ordinary homes from 1993–2003. The statistics for 1998 is missing due to lack of comparable data. Sources: SCB, 1994, National Board of Health and Welfare, 1995c, National Board of Health and Welfare, 1996b, National Board of Health and Welfare, 1997c, National Board of Health and Welfare, 1998, National Board of Health and Welfare, 2000a, National Board of Health and Welfare, 2001a, National Board of Health and Welfare, 2002a, National Board of Health and Welfare, 2003b, National Board of Health and Welfare, 2004b.

Thus, it does not seem as if previous measures that entailed housing with support, has been replaced personal assistance. On the contrary, all types of measures except nursing homes, have increased. The increase in the number of places in group homes between 1992 and 1996 is probably linked to the dismantling of nursing

homes, but that only explains just under half the increase. The dismantling of the nursing homes was in principle concluded before the year 2000, and therefore cannot serve as the explanation for the continued development of residential arrangements with special service. Neither does the extension of the client categories represent a major part of the increase.

	1999	2000	2001	2002	2003
MUNICIPAL COSTS					
Measures according to SoL/HSL	5 300	5 300	5 500	5 900	5 800
<i>In ordinary housing</i>	2 500	2 600	2 800	3 000	3 000
<i>Special housing</i>	2 800	2 700	2 700	2 900	2 800
Measures according to LSS	20 400	21 800	22 600	23 600	25 100
<i>Housing according to LSS</i>	11 600	12 000	12 300	12 600	13 300
<i>Daily activities</i>	3 700	3 700	3 900	4 000	4 100
<i>Personal assistance (municipal cost for LSS and LASS)</i>	2 400	3 500	3 600	4 200	4 600
<i>Other activities according to LSS</i>	2 800	2 600	2 800	2 800	3 100
TOTAL	25 700	27 100	28 100	29 500	30 800
STATES COSTS (LASS)	5 300	6 100	7 000	7 900	8 700
TOTAL COSTS	31 000	33 200	35 100	37 400	39 500

Table 4: The municipality and state costs of support measures for people with functional impairments in set prices (SEK million). Index: SCB's Consumption Index for Care for the Elderly and the Disabled, prices from 2003. Source: The National Board of Health and Welfare, 2005c and The Swedish Social Insurance Agency, 2005.

The new people that has moved into residential arrangements with special service rather seems to consist of people with intellectual impairments who previously had no residence with support from salaried staff.

In brief, in the light of the above section we note that the growing number of people that receive personal assistance seems to be part of a general increase of people receiving support due to functional impairments. It is not possible to find proof of any transfer from other public and national support measures to personal assistance, either at the implementation of the reform or later, if we ignore a minor fall in measures through home-help service for a couple of years immediately after the

REVIEWING MEASURES AND COSTS

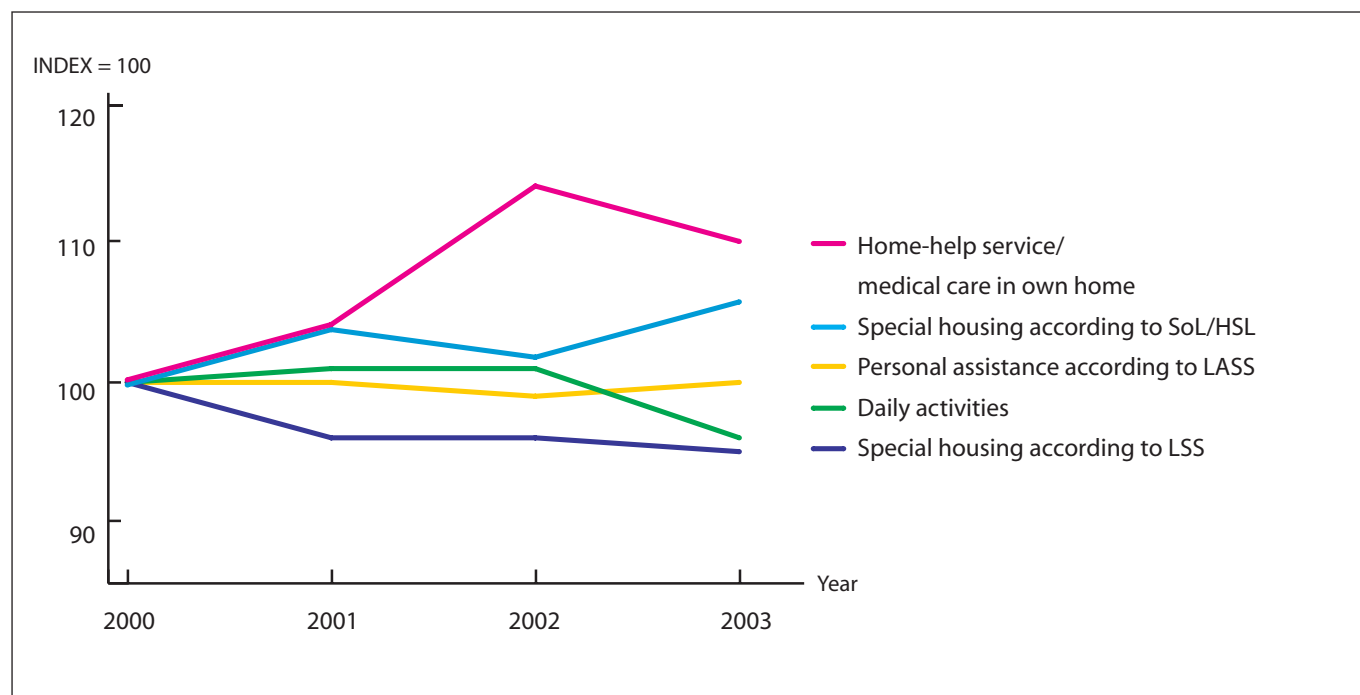


Chart 8: Comparison of the cost development in set prices for support measures according to SoL/HSL/LSS/LASS on average per individual, 2000–2003. The calculations can be found in appendix 3. Index: SCB's consumption index for care of the elderly and the disabled, prices from 2003. Sources: National Board of Health and Welfare, 2004c, National Social Insurance Board 2004

reform coming into force (see chart 7). As will become clear in section 3.3 however, some aspects of the large costs in connection with the introduction of the reform stem from the fact that different special solutions in the municipalities, which have not been presented on a national level, are now being replaced by personal assistance according to LSS/LASS.

3.2 Cost development

The fact that more and more people are granted various measures due to their functional impairments is reflected in society's cost for such service. The cost of the most common support measures to people with extensive functional impairments has grown by 27 percent between 1999 and 2003. The total cost of personal assistance according to LSS and LASS, grew by 73 percent from 1999–2003 (see table 4).

The total cost is determined by the number of people receiving the support measure, the extent of it that each individual receives, and the price for a certain amount of the measure (e.g. one hour or one day).

In chart 8, we compare the average cost per user of the measures, home care/medical care in the home, special housing according to SoL/HSL, personal assistance according to LASS, daily activities and special housing according to LSS. We used the costs from 2000 (index 100) as our starting point, and then tracked developments in average cost in set prices per person for each measured person until 2003. None of the support measures that we studied showed a particularly steep rise in cost per person, but special housing according to SoL/HSL has seen the biggest increase. The cost development per person for personal assistance is, in principle, zero, while it is negative for the other support measures, which could explain why the total increase for those measures are not very large, in spite of the growing number of people receiving them.

It is desirable to be able to break down cost developments further and examine the development of the cost per hour for services rendered, but that is unfortunately only possible for the personal assistance measure. The special housing calculates the cost per day, but that covers different amounts of service. The daily cost for

REVIEWING MEASURES AND COSTS

	1995	1999	2003
Granted hours, average per week	67	82	94
Number of people granted assistance according to LASS	6 876	9 085	11 910
Cost of personal assistance according to LASS, SEK thousand per year	5 220 000	7 140 000	11 165 000
Average cost per person, SEK per year	760 000	786 000	937 000
Cost per hour, SEK	217	205,35	199,26

Table 5. Summary 1995, 1999 and 2003 in set prices. Index: SCB's consumption index for care of the elderly and the disabled, prices from 2003. Sources: The Swedish Social Insurance Agency, 2005.

an LSS home could cover anything from a counselling and supporting measure for one hour, to continuous round-the-clock support. Therefore, it is not possible to divide it by 24 and get an hourly cost for the actual service. As mentioned previously, the Association of Local Authorities has initiated a project to develop a method for measuring the cost of one hour's home-help service. The method has so far not been used for any national follow-ups. However, the project has presented an approximate costing for the participating municipalities; SEK 300–400 per hour including attendant costs and overheads.²⁸

It is worth noting that the average salary increase for personal assistants and nurse's assistants in the municipalities and county councils from 1994–2003 was 32 percent²⁹, compared to a 22 percent increase in the hourly price for personal assistance during the same period. So, there are grounds for arguing that the assistance benefits have been undermined since the initial stages of the reform.

To conclude, we note that the total cost increase for personal assistance is still significant (see table 5). But when looking at the cost development per person, we see that the increase is smaller. In set prices, the hourly cost for personal assistance has fallen.

3.3 Why was the assistance reform more expensive than predicted?

The National Board of Health and Welfare has brought attention to several important factors underlying the fact that personal assistance initially became so much more expensive than predicted. Some of them are worth noting.

In the preliminary work of the reform, the need of support was underestimated. The estimates that were made, were based on the number of hours of home-help service the people in the study received. In the inquiry that forms the basis of the report from the National Board of Health and Welfare "The state assistance benefit – why so many hours", it was concluded that those who were granted assistance in 1994 received support measures from the social services during an average of 32 hours per week in 1993. Adults had an average of 34 hours per week and children received 25 hours.³⁰ The average number of granted assistance hours was significantly higher as early as in 1994 (approximately 66 hours) and has grown further since then.³¹

It is not possible to say with any certainty what measures those who have personal assistance today received earlier, as there are no longitudinal studies made in the area. In the above-mentioned report however, there is mention of a study comprising 94 people in seven municipalities, studying what kind of measures people who received personal assistance in 1994, received the previous year. This study showed that among those who were granted assistance benefits in 1994, around 80 percent received some form of support measure from the social services during the autumn of 1993. About one third of those had either home-help service or a carer who was a relative. Approximately one fifth of them

²⁸ Association of Local Authorities, 2003

²⁹ Trade Union Confederation, 2005

³⁰ National Board of Health and Welfare, 1995a. p. 18

³¹ National Social Insurance Board, 2004

received either companion service, relief service or personal assistance/care according to SoL. The people in the study had, by getting access to assistance benefits, except in exceptional cases continued to receive support from the social services.³²

Thus, it is apparent that many of those who first applied for personal assistance not only had home-help service, but also support from relatives or some kind of municipal personal assistance before the reform. The fact that some of those who previously had home-help service have now switched to personal assistance is entirely in accordance with the intention of the legislators.

The number of people with home-help service and/or hospital care in the home fell by 5,100 from 1993–96. After 1997, the number of people with home-help service and/or hospital care in the home has again increased – much like other measures have – to meet the need for continuous daily support and service (see chart 8).

Another important factor behind the unexpectedly large increase in demand is that many of those who previously were granted personal assistance were living in their parents' home and had their support and service provided by relatives. More than 14,000 people were registered in the Social Welfare Act in 1992, but did not reside in nursing homes or group homes. It is reasonable to assume that many of those received unpaid support from close relatives before personal assistance became a right. The statistics on types of housing for the functionally impaired who did not reside in special housing disappeared with the introduction of LSS, so we do not know how those people live and receive support today, but it is probable that many of them are receiving personal assistance.

A list of explanations should also include the fact that many of the people eligible for assistance today had a need that corresponded to personal assistance even before 1994. Personal assistance has, in practice, been an alternative since the beginning of the seventies for some of today's JAG members. The National Board of Health and Welfare has noted that personal assistance have been in use since the mid-eighties in some municipalities.³³ As there was no documentation on a national

level, it is difficult to determine how many people were receiving assistance before 1994. The STIL project started in 1987 to show that assistance users in groups can be employers and are able to produce better quality for the same cost as for home-help service. 22 assistance users and six municipalities, among others Stockholm, participated. Trials with personal carers were made in Ekerö and on Gotland. From 1987–88, eleven children on Gotland and five in Ekerö had personal carers and an unknown number of people had individual agreements with their municipalities about tailored support. In addition, for a long time there has been, and still is, several different forms of financial compensation and grants to relatives who provide support and service to family members in the home. Disablement and care allowance, employment of relatives and grants to relatives are some examples of those.

In conclusion, it should be noted that the fact that relatives previously provided a large part of the care for very little or no compensation, constitutes the single most important explanation as to why the assistance reform initially became more expensive than predicted, which is appreciated by the National Board of Health and Welfare, among others³⁴. This is further confirmed by JAG's own inquiry presented in the following section.

3.4 Survey of members of the JAG User Cooperative

JAG's subassociation, the JAG User Cooperative arranges personal assistance to the members who so wishes.

In June 1995, a survey was conducted among the 66 people who received assistance through JAG, enquiring about the forms of support and service they received in 1993, i.e. one year before the assistance reform. In 2005 the same questions were asked of the 54 users who were still alive.

35 of the interviewees were 18 or younger in 1993. Out of those, 26 people then received some form of continuous daily personal support from an employed relative, municipal personal assistance or something similar. 22 people spent a few days per month in a temporary nursing home. Two people had no support needs at this time. They acquired their impairments between 1993 and 1995.

³² National Board of Health and Welfare, 1995a. p. 18 ff

³³ National Board of Health and Welfare, 1997a. p. 72.

³⁴ National Board of Health and Welfare, 1997a.

REVIEWING MEASURES AND COSTS

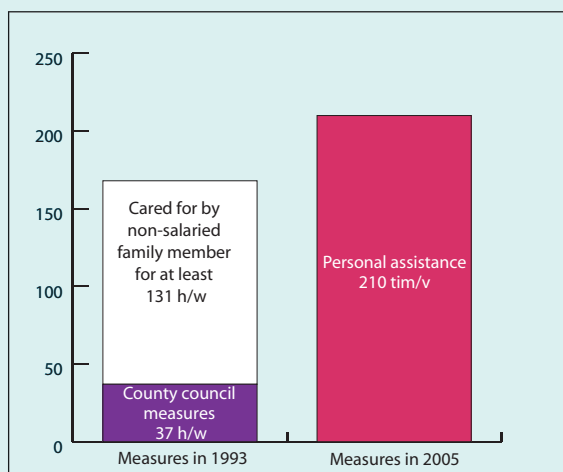


Chart 9. Person 1, measures in 1993 and 2005 respectively

Person 1, born in the fifties. After having been severely injured at the end of the eighties, he was offered a place in long-term care. He spent almost a year in care before moving to his parents' home. The county council provided support measures for 37 hours per week. The rest of the time, he received support and care from his relatives. In 1994, he moved to his own home and was granted personal assistance for 210 hours per week. The number of hours remained unchanged in 2005.

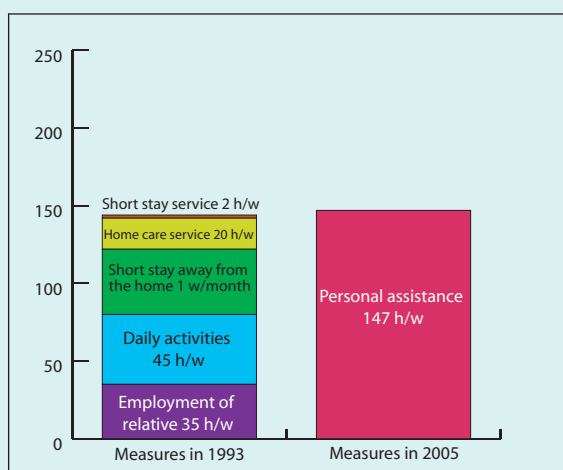


Chart 10. Person 2, measures in 1993 and 2005 respectively

Person 2, born in the sixties. In 1993, when he was almost 30, he still lived with his parents. He had been granted a number of different support measures: employment of relatives, daily activities, short stays away from the home, home-help service and short-term supervision in the afternoons, all amounting to a total of approximately 144 hours per week. In the activities, he received support and service from the staff at each activity. In 2005, he was granted personal assistance for 147 hours per week, which corresponds to round-the-clock support with sleeping on-call attendance. He lives in his own home.

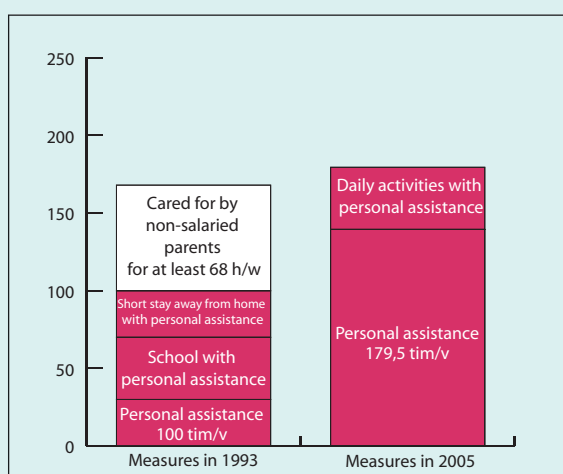


Chart 11. Person 3, measures in 1993 and 2005 respectively

Person 3, born in the seventies: In 1993, when she was 16 years old, she was granted personal assistance for 100 hours per week. The assistants were present in school, at leisure activities and at home. The rest of the time, she received care and support from her parents. In 2005, she has moved to her own home and has been granted personal assistance for 179.5 hours per week.

REVIEWING MEASURES AND COSTS

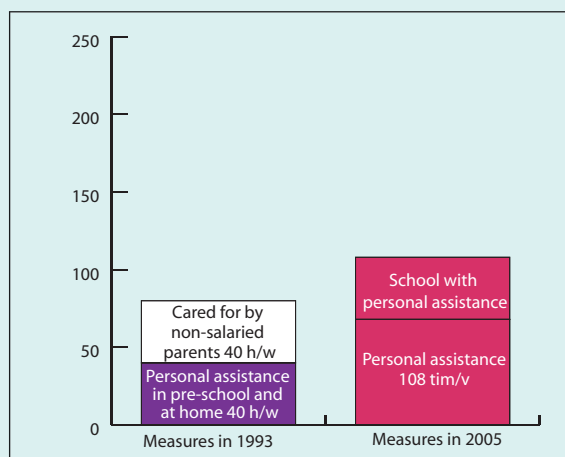


Chart 12. Person 4, measures in 1993 and 2005 respectively

Person 4, born in the eighties. In 1993 he was granted personal assistance for 40 hours per week in pre-school and at home when needed. The parents estimate their unpaid support, in addition to the "normal" parental responsibilities for a child of the same age, to about 40 hours per week. In 2005 he still lives at home and has been granted personal assistance for 108 hours per week. The assistant also accompanies him to school.

31 of the interviewees were 19 or older in 1993. In this group, 18 people had some form of continuous daily personal support at the time of the first inquiry. Nine people spent a few days per month in a temporary nursing home. Three people lived in a group home, two had residential service and two people were in hospital.

The material in the JAG survey is comprehensive and its large variations clearly show that the situation of each individual is unique. In order to illustrate how the support measures for the interviewees changed between 1993 and 2005, we have selected four people born in the fifties, sixties, seventies and eighties respectively (see charts 9–12).

The extent of the support has changed significantly for three of the four individuals. For the person born in the fifties, the support increased significantly in connection with the reform, as a then untenable situation could be solved by providing a home for the user and personal assistance. However, the extent of the support has not changed since then.

The person born in the sixties has approximately as many hours of support in 2005 as in 1993, with the difference that personal assistance today has replaced all the other support measures, even daily activities.

For the person born in the seventies, the assistance increased gradually in connection with her growing older and eventually moving to her own home.

For the person born in the eighties it is also obvious that the need increases with age while, at the same time, the

parents' responsibility, naturally, decreases. In 1993, he had not yet started school and today, he is in his late teens.

The survey clearly shows that the assistance reform, for people with extensive functional impairments, means that the unpaid work of close relatives is replaced by personal assistance. For most of the interviewees, it consisted of parents providing care for adult children to the equivalent of one, or sometimes several, full time positions per person. It was also clear that with personal assistance, many varied (and often badly coordinated) measures could be replaced by one single individually tailored support measure. It provided users with both continuity and flexibility. But it was not unusual to receive personal assistance or its equivalent before 1994 as well. In those instances, the reform led to improved security, and sometimes also an opportunity to have a larger portion of the needs met.

The results of this survey among members of JAG will be published in their entirety during 2006.

3.5 Will the increasing costs be mitigated?

It is a fact that the costs of personal assistance with benefits according to LASS continue to grow eleven years after its introduction.

The steep increase during the first few years is of course linked to the fact that it was a wholly new measure that "started from scratch". In table 5, we present the cost

REVIEWING MEASURES AND COSTS

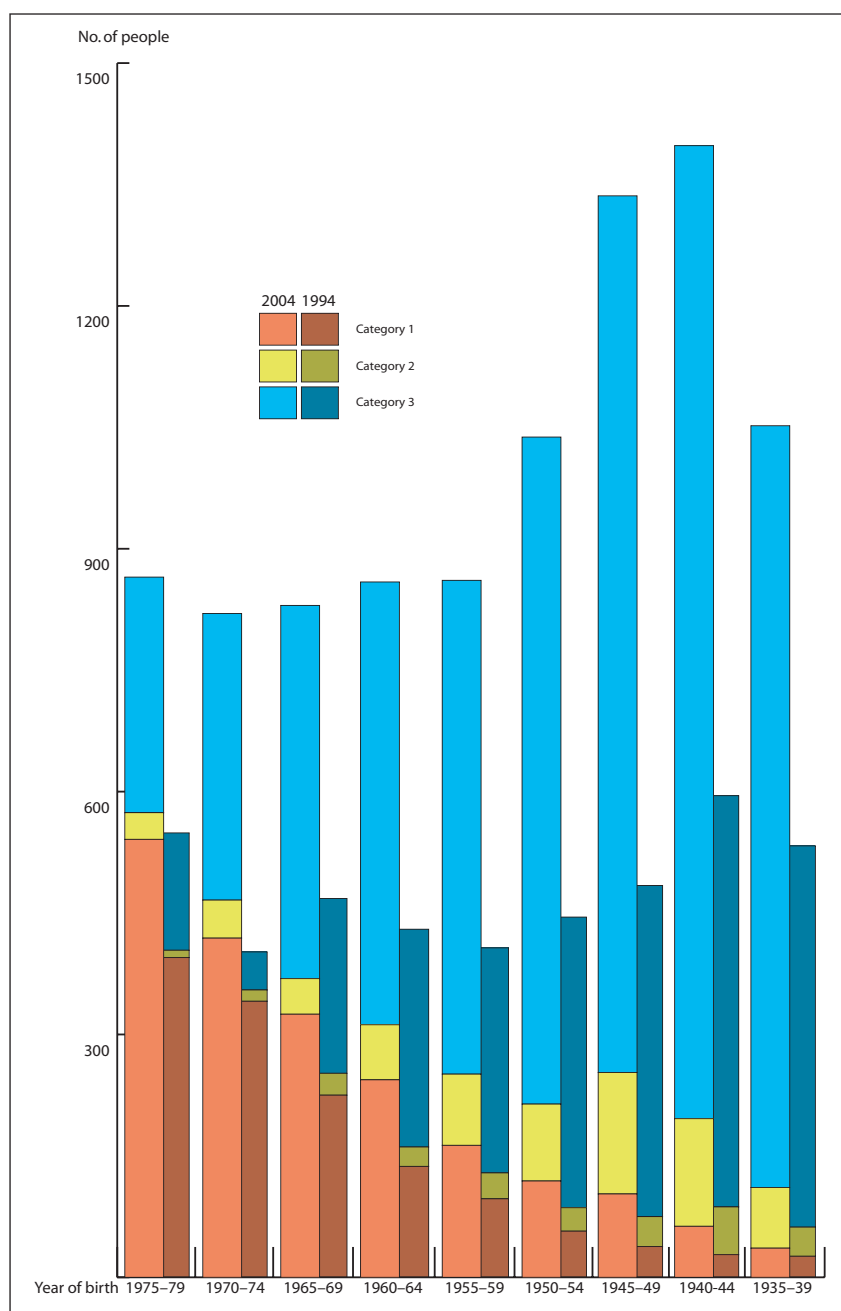


Chart 13: Age groups and client categories. Comparison between 1994 and 2004.
Source: The Swedish Social Insurance Agency

development from 1995–2003, using 1999 as the point of reference. We have chosen to leave out 1994, due to the less than reliable statistics from this first year. If you look at the trend from 1999, the cost of assistance according to LASS has grown by 56 percent compared

to an increase of 114 percent since 1995.

In their forecasts, the Swedish Social Insurance Agency is predicting a smaller increase in the future. There are plenty of indicators of this. Both the number of granted hours as well as the number of people receiving assistance are growing, but not to the same extent as during the first few years.

The number of people eligible for assistance is growing

The number of people eligible for assistance is growing for all age groups, but not to same extent in all of them. The number of children between 0 and 14 with assistance benefits has decreased from 18 percent in 1994 to 13 percent in 2003, while assistance users between 55 and 64 grew by 165 percent during the same period. The highest increase for the period can be found in the 65+ group, due to the change in legislation in 2001, making it possible to keep personal assistance even after turning 65.

Chart 13 shows how the increase is distributed across generations. The source is the Swedish Social Insurance Agency statistics of age distribution among those eligible for assistance. It is divided into age groups of five years each, which means that the development for the "same" age group can be reviewed for both 1994 and 2004. We have not included the youngest and the oldest groups as the statistics only include people under 14 and over 65 respectively, making it impossible to track them in the same intervals as the other groups. This is why the chart starts with people born in 1975 and ends with those born in 1939. The chart

makes it clear that the largest part of the increase can be found among those who are born between 1940 and 1954, i.e. those who are between 51 and 65 today. The younger generation (born from 1975–79) who came into the system early, and constituted the single largest

group in 1994, has not increased nearly as much as the others and it is now one of the smallest groups.

Considering that the older age groups constitute a growing share of the people eligible for assistance, it is probable that it concerns people who received injuries during the period, as well as people who previously had less extensive functional impairments but whose service needs have grown, thus making them eligible for personal assistance. It could for example be people with neurological disorders that gradually worsen.

If we look at client category 1, the relationship is reversed. Here, the group of people born in 1975–79 sees the greatest increase. Those people are between 26 and 30 today. The increase is probably due to the fact that they are in greater need of support as adults. In client category 1, we find a lot of the people with the most extensive and complex functional impairments. It is reasonable to assume that one of the reasons for that group being the largest of the younger age groups is simply the high mortality rate. On the other hand, personal assistance is a far better support measure than what was previously available, so we may expect a significantly improved lifespan in the future. And that is of course something very positive.

The distribution across the various client categories varies greatly between the age groups. At 30, the share of client categories 1 and 3 are approximately 47 percent. For client category 1, this share is reduced rapidly with age, while the opposite is true for those in client category 3. In 2003, a little over 1,000 people over the age of 65 received assistance benefits. Only ten percent of those are found in client categories 1 and 2.

In an analysis from 2001, the Swedish Social Insurance Agency argued that progress in healthcare leads to many people with functional impairments having longer lives. They argued that improved healthcare leads to more and more people surviving severe conditions and accidents, but receive lifelong functional impairments as a consequence, and also that more children survive premature birth and birthing injuries that lead to extensive functional impairments.³⁵

The argument about a growing number of infants

with extensive functional impairments is contradicted by research that shows that the number of children with cerebral palsy has been decreasing in Sweden since the mid-eighties. Anders Hjern, paediatrician and adjunct professor working at the Huddinge University Hospital and the Epidemiology Centre at the National Board of Health and welfare, argues that cerebral palsy is a good marker for extensive functional impairments and that it indicates that fewer functional impairments in children are due to birthing injuries or premature birth. This is probably due to the continuous quality developments that have taken place in the field over the last few decades. Not only are more children saved, says Hjern, the ones who are saved are also taken care of better, which leads to fewer or less extensive functional impairments. Another group of functional impairments where we have seen a decrease is instances of spina bifida, which is probably due to selective abortions after antenatal diagnostics with ultrasound. As regards children with Down's Syndrome, the number of children born has remained level since the seventies while the survival rate has increased thanks to the progress made in paediatric heart surgery over the last few decades.³⁶ In general, the developments in maternity and newborn care should not lead to more children needing personal assistance.

More hours granted

The average cost per person eligible for assistance is also growing due to the fact that the average number of granted hours is increasing. From 1994 to 2005, the average number of granted assistance hours have grown by 52 percent. The latest data on average number of hours can be found below³⁷. Client category 2 is granted more hours per week on average than client categories 1 and 3.

Client category 1: 99.4 hours per week

Client category 2: 122.9 hours per week

Client category 3: 98.6 hours per week

The analysis by the Swedish Social Insurance Agency also showed that the highest number of hours was granted to

³⁵ National Social Insurance Board, 2001. p.16 ff.

³⁶ Anders Hjern, Huddinge University Hospital, 2005.

³⁷ The Swedish Social Insurance Agency database, STORE, May 2005

people who already received personal assistance. Those who received newly granted assistance, had a lower average number of hours. The main explanation was considered to be a worsening of the condition for the people eligible for assistance. Among the assistant users, neurological diagnoses dominate, for example MS that often is progressive. This means that many need more assistance hours as they grow older and the illness progresses.

The Swedish Social Insurance Agency also points to the fact that the availability of personal assistance has opened up new possibilities for people with functional impairments and consequently gradually increased the demand for assistance. Due to limited living conditions, some people with functional impairments applied for too few assistance hours initially. After a time, those people realised that through personal assistance they could improve their living conditions more than they had thought possible. The Swedish Social Insurance Agency also writes that membership in user cooperatives increases awareness of the possibilities to live an active life, which among other things leads to requests for moving to a home of their own and thus also increasing their need for personal assistance. The Swedish Social Insurance Agency also noted that the biggest single reason for the growing number of assistance hours among those already granted personal assistance, was leisure activities.

3.6 Discussion

In the twelve years since the right to personal assistance was introduced, the growing costs have continuously been discussed as the original predictions have turned out to be incorrect. Neither the expected number of hours, nor the number of people has been in line with the original estimates.

The survey among JAG members who have been receiving assistance since 1994 shows, in line with previous surveys, that many people before the reform had a significant part of their care and service needs met through unpaid work by relatives. People with extensive functional impairments were often dependent on a large number of different support measures. For many, those measures have now been replaced by personal assistance, in some instances combined with daily activities, etc.

In this survey, we are not intending to prove that this leads to synergetic benefits that can be measured in financial terms, but it is not unreasonable to think that it might. There are also other probable economic benefits that may be more difficult to estimate, in the form of less healthcare needs due to a better and more tailored personal care, as well as a lessening of the burden for relatives, leading to less absenteeism, etc.

We will return to this line of reasoning in the next report.

4. CONCLUDING ARGUMENTS

Our conclusion is that there are no financial reasons to provide people with severe functional impairments alternatives to personal assistants. The cost trend can be partially explained by increasing needs, but also by a growing awareness that people with functional impairments should be offered support and service in a manner enabling them to enjoy freedom of choice, self-determination and integrity. It also comprises the notion that the previously unpaid work of close relatives should be justly compensated.

Our conclusion is that the growing need for assistants primarily stems from the fact that people with functional impairments have a longer lifespan due to more extensive support measures, improved medical care and increased access to various technical aids. This applies both to people with neurological conditions as well as those who, for other reasons, have extensive functional impairments.

Overall, this contributes to the growing number of people with functional impairments. The average number of granted assistance hours also increase year by year. The cost of assistance per hour in maintained prices, however, has decreased.

The age group comprising 62-66 year-olds is the single largest age group among people eligible for assistance, as you cannot be granted assistance or extend the number of hours after the age of 65. Irrespective of the limit set, it is probably inevitable that a peak will be reached for the age group preceding that limit.

Through the assistant reform, adults with severe functional impairments are able to live a life without being completely dependent on spouses, parents or other relatives. Even in cases where a relative is employed as assistant, there is freedom of choice, in the sense that all personal assistants are salaried employees and thus replaceable.

Publicly funded welfare services guarantee that everyone is covered the social insurance system, and that everyone has the right to receive the support they need without being at the mercy of charity and voluntary efforts. The fact that support for people with functional impairments before the assistance reform to such a great extent was dependent on the unpaid work of close relatives, tells us that this objective was not met. The assistance reform transformed unpaid work into salaried

employment. Hence, the consequent increase in openly reported cost only stands to reason.

The fact that almost all parents with small children work, and that using child care services is the norm in society as a whole, probably leads to parents with impaired children being more inclined to apply for various support measures. They are no longer expected to give up their professional careers to care for their children, which for most people is not a viable option for economic reasons. This is reflected in the growing number of LSS (Act concerning Support and Service for Persons with Certain Functional Impairments) measures that primarily target children.

For every new generation of eighteen-year olds in the next few decades, the number of parents refusing to carry out unpaid work will increase. Fewer and fewer mothers will provide around-the-clock support for their adult impaired children without receiving financial compensation when there is an opportunity to receive a pensionable income as a personal assistant – this is also in line with the intentions of the reform to promote gender equality.

Assuming that the ambition is to meet those needs, there is no money to be made from trying to find alternatives to personal assistants for those with the most severe functional impairments and the greatest needs. A group home does not, as shown in chapter two, lead to any savings. Instead it will mean significantly reduced flexibility and self-determination for the individual, compared to retaining the system of personal assistants; neither is homecare more cost-effective. Thus, there are no financial arguments for directing people to alternative measures, as long as the basic values that lie at the heart of the assistance reform are maintained.

CONCLUDING ARGUMENTS

Our comparative study of different measures should not be interpreted as an argument in favour of providing personal assistants for all. Instead, our conclusion is that there are no reasons for directing people to collective measures on the grounds of efficiency or cost-effectiveness, but that there should be real freedom of choice also for people with functional impairments.

Naturally, it is difficult to draw any conclusions about the future cost trends. It may be that the entire need is not yet covered. It could also be that the present number of people eligible for personal assistance, correspond to the number of people in actual need for it. That would mean that the increase in the number of people eligible for personal assistance levels out and that the costs/numbers will remain level in the future.

This report is entitled “The price of freedom of choice, independence and integrity”, referring, of course, to

the three cornerstones of LSS (the Act concerning Support and Service for Persons with Certain Functional Impairments). But the growing cost over the last few years is also the price for increased equality for those women who previously provided the lion share of the support and care of close relatives with functional impairments.

The extent of the unpaid work performed by those women was not apparent to the legislators when the reform was implemented; but today it has become clear. Through the assistance reform, parliament made an important choice for the future. If the reform were to be weakened as regards, for example, the definition of client categories or the needs assessment, the consequence would inevitably be a return to the old system of limited freedom, dependency and alienation, for the functionally impaired clients and their families alike.

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Appendix 1

Municipal survey

Resident	No. of residents	Target group	Staff intensity	Night staff	Total benefit	Total cost	Daily cost per person	Executor

I request information about the types of housing that primarily target people with extensive functional impairments – primarily intellectual impairments combined with physical impairments and communication difficulties.

Write the name of the home in the first box, the number of residents per year in 2004, target group – types of impairment and age if relevant, daily staffing, night-time staffing – numbers on call or awake, benefit 2004, costs 2004 (i.e. the result) and daily cost per person. Last box is the executor if not the municipality.

If you have any questions, please contact:

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Appendix 2

Number of people receiving measure according to LASS and LSS per client category between 1996 and 2004

	1996	1997	1998	1999	2000	2001	2002	2003	2004
LASS	7 666	7 861	8 102	9 085	9 684	10 849	11 616	11 910	12 751
Category 1	2726	2 781	2 990	3 149	3 346	3 575	3 886	4 039	4 380
Category 2	405	433	478	550	597	663	694	694	748
Category 1+2	3 131	3 214	3 468	3 699	3 943	4 238	4 580	4 733	5 128
Category 3	4523	4 672	4 965	5 300	5 630	6 447	6 867	6 991	7 393
All with LSS	39 694	41 640	45 503	43 991	45 527	47 092	48 598	51 510	52 900
Category 1	32785	33 608	35303	34 456	35716	37 143	38 425	40 884	
Category 2	686	787	1024	966	1054	1 210	1 302	1 412	
Category 1+2	33471	34 395	36 327	35 422	36770	38 353	39 727	42 296	
Category 3	6223	7245	9176	8 569	8747	8 739	8 871	9 214	
Advice & counselling	23 977	23 114	21745	18 603	16 435	i.u.	11 932	11 660	11 162
Category 1+2	22 887	21 761	20 001	16 859	14 802	i.u.	10 285	9 951	9 425
Category 3	1090	1353	1775	1744	1633	i.u.	1 647	1 709	1 737
Personal assistance	3 309	3 853	3 929	4 536	4 228	4 329	4 334	4 592	3 8961
Category 1+2	1 644	1 859	1 762	2 068	1 868	2 028	2 000	2 066	
Category 3	1665	1 994	2167	2468	2360	2 301	2 334	2 526	
Companion service	3 336	4 621	6412	7384	7822	8 075	8 466	9 156	9 368
Category 1+2	1 948	2 784	3 899	4 453	4 738	4 991	5 067	5 970	
Category 3	1388	1 837	1400	2931	3084	3 084	3 159	3 186	
Personal contact	10502	11 813	13720	13397	13559	13 975	14 483	15 171	16 055
Category 1+2	9 733	10 779	12 249	11 787	11 956	12 361	12 871	13 491	
Category 3	765	1034	1471	1610	1603	1 614	1 612	1 680	
Relief service	2 189	2 780	3 404	3 615	3 649	3 627	3 533	3 648	3 654
Category 1+2	1 689	2 175	2 690	2 840	2 904	2 957	2 921	3 076	
Category 3	500	605	714	775	745	660	612	572	
Temporary stay	7 541	8 012	8 749	9 436	9 786	9 637	9 941	10 371	10 485
Category 1+2	7 077	7365	7981	8471	8772	8 724	9 050	9 543	
Category 3	464	647	768	965	1014	913	891	828	
Short term care	2 762	2 660	2 837	2 778	2 983	3 080	3 418	3 954	4 426
Category 1+2	2 704	2595	2749	2684	2869	2 941	3263	3831	
Category 3	58	65	88	94	114	139	155	123	
Resident children	1 684	1 510	1 380	1 295	1147	1 112	1 193	1 289	1 241
Category 1+2	1 640	1480	1350	1252	1103	1 074	1 141	1 238	
Category 3	44	30	30	43	44	38	52	51	
Resident, adults	14 715	15 072	16 162	16 422	16 907	17 486	17 980	18 992	19 852
Category 1+2	14 155	14 256	15 145	15 204	15 666	16 112	16 527	17 938	
Category 3	560	816	452	1218	1241	1 374	1 453	1 627	
Daily activities	17 759	18 378	19 754	19 825	20 528	21 113	21 653	23 150	24 057
Category 1+2	17 759	18378	19 645	19 776	20 456	21 042	21 550	23 075	
Category 3	0	i.u.	109	49	72	71	103	75	

When gathering statistics for 2004, the National Board of Health and Welfare sent a letter to the municipalities with a clarification about which people receiving personal assistance to be reported in the statistics. It resulted in extensive amendments, which is why statistics for this measure cannot be compared to corresponding data from previous years. After 2003, no information about the LSS support users' client categories is kept by the National Board of Health and welfare, except for advice and personal counselling, which is why there is no dision by client category for 2004. Sources: National Board of Health and welfare, 1996, National Board of Health and welfare, 1997b, National Board of Health and welfare, 1999, National Board of Health and welfare, 2000a, National Board of Health and welfare, 2001a, National Board of Health and welfare, 2002a, National Board of Health and welfare, 2003a, National Board of Health and welfare, 2004a, National Board of Health and welfare, 2005b, National Board of Health and welfare, 2005:5, The Swedish Social Insurance Agency, statistics on assistance benefits.

Appendix 3

Index for costs per person receiving measures for people with functional impairments
Basis for estimates in chart 8.

	2000	2001	2002	2003
Cost/person in ordinary housing	<u>170859</u> 170859 = 100	<u>177860</u> 170859 = 104	<u>194707</u> 170859 = 114	<u>187577</u> 170859 = 110
Cost/person in special housing according to HSL/SoL	<u>449083</u> 449083 = 100	<u>467994</u> 449083 = 104	<u>455934</u> 449083 = 102	<u>474425</u> 449083 = 106
Cost/person in special housing according to LSS	<u>656885</u> 656885 = 100	<u>629180</u> 656885 = 96	<u>626454</u> 656885 = 96	<u>625176</u> 656885 = 95
Cost/person with daily activities	<u>182404</u> 182404 = 100	<u>183418</u> 182404 = 101	<u>183552</u> 182404 = 101	<u>175633</u> 182404 = 96
Cost per person with personal assistance*	<u>18721</u> 18721 = 100	<u>18613</u> 18721 = 100	<u>18453</u> 18721 = 99	<u>18730</u> 18721 = 100

*The cost for personal assistance is based on the average number of hours times average cost.
Index: SCB's Consumption Index for Care of the Elderly and the Disabled, prices from 2003.
Sources: National Board of Health and welfare and The Swedish Social Insurance Agency

Appendix 4

SCB's Consumption Index for Care of the Elderly and the Disabled

SCB's Consumption Index for Care of the Elderly and the Disabled is indirectly calculated by dividing current prices with set prices for public consumption within the field.

It is calculated in the same way as the GDP deflator, which constitutes the GDP in current prices divided by the GDP in set prices. So it is not a directly collated price index for the price development of the goods and services included.

Consumption consists of the total production of services, minus the sale of activities for certain fees, for example elderly care, that has taken place during the period.

The total production in activities that are not sold in a market at market prices is calculated with the help of the costs of producing this activity. The lion share of the costs consists of labour compensation, and also the costs of procuring materials and services for the running of operations, as well as capital wear on invested capital. The information is collected from the municipalities in current prices, i.e. the price in each respective year.

In the public sector, calculating set prices is done with the help of volume development of the number of worked hours. This provides a value in current prices, which is then divided by the calculated value in set prices.

Source:

*Birgitta Magnusson, National accounting, SCB,
E-mail correspondence, January 2006*

The JAG association is a national non-profit association for people with several major functional impairments and an impaired intellectual ability. With the support of the Swedish Inheritance Fund, the association runs a project for collecting and disseminating knowledge of personal assistance for people with intellectual impairments.

The Swedish assistance reform from 1994 is being reviewed by the government's Assistance Committee. Their commission includes searching for a way of mitigating the cost development of the reform.

In the light of the committee's commission – and the debate over the past few years about the cost development of personal assistance according to LASS – JAG has performed a cost analysis of the support measure and compared it to those of other measures for people with functional impairments and extensive needs for support and service.

The report makes clear that the growing number of people needing personal assistance, is a part of a general increase in the need for support measures for people with functional impairments – and that it is no less expensive to provide extensive assistance needs through other measures. The cost of a place in a group home for a person with extensive functional impairments often exceeds the cost of personal assistance for the same person. This is in spite of the fact that personal assistance means greater flexibility and freedom of choice for the individual.

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