

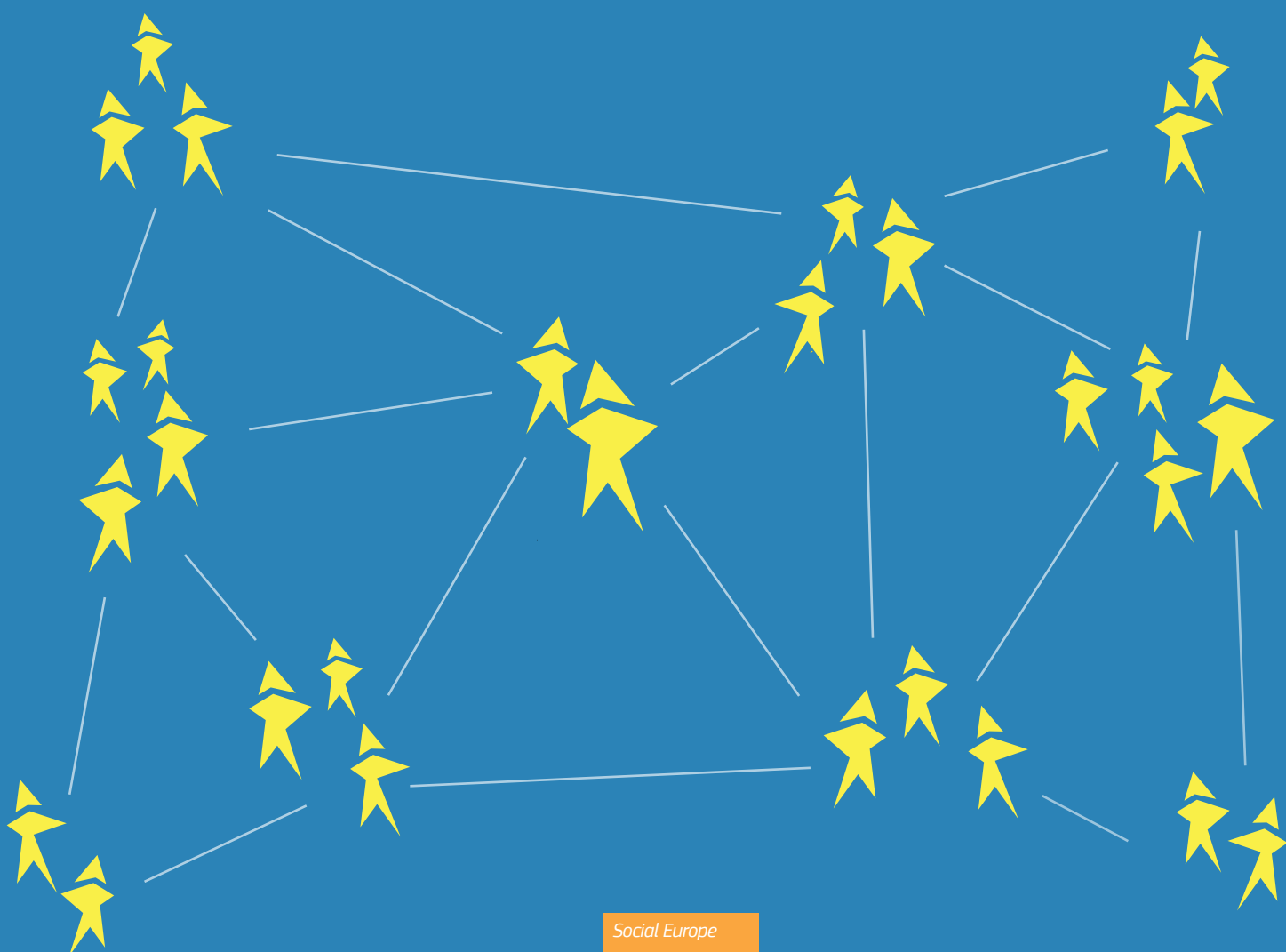


EUROPEAN SOCIAL POLICY NETWORK (ESPN)

Social protection for people with disabilities

Sweden

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Summary

This report analyses some important cash and in-kind social protection provisions available to adults with disabilities (i.e. aged 18 or above). There are other important provisions available to them in other areas not covered in this report. In line with Article 1 of the UN Convention on the Rights of Persons with Disabilities, "people with disabilities" should be understood as "*those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others*".

A central aim of Swedish disability policy is to provide publicly funded, widely available services – in-kind rather than cash benefits. The services are based on people's needs, regardless of economic means and family resources. All people in Sweden with needs for care and support, irrespective of age and type of disability, are covered by the Social Services Act. People with severe disabilities can also under certain conditions be covered by the Act Concerning Support and Services for People with Certain Functional Disabilities (LSS) and by the Assistance Allowance Act (LASS).

The general social protection benefits – pension schemes, *Arbetslöshetsförsäkring* (unemployment insurance) and *Försörjningsstöd* (social assistance) – cover the entire population without additional compensation for people with disabilities. People with disabilities may be disadvantaged in, for example, pension schemes due to lower incomes during the life course and consequently lower pensions.

There exist a few cash benefits aimed specifically at people with disabilities, including *Sjukersättning* (sickness compensation) and *Aktivitetsersättning* (activity compensation). There are several issues with these two benefits, such as the assessment of the applicant's work capacity, which is a key eligibility criterion. The person's work capacity is assessed by comparing the disability with an all-encompassing definition of the labour market, which can lead to a situation where people who may not have a real possibility of finding a suitable job are denied compensation. A recent inquiry therefore proposed that the scope of the labour market be redefined.

A benefit exists to cover disability-related costs such as healthcare expenses, but is limited to disabilities that have arisen before age 65, creating an age gap in availability. There is also a housing adaptation grant, which is nationally available but with local variations and often poor management. Assistive devices are also nationally available but with local variations; in this case variations concern whether or not fees are charged, creating geographical inequalities in the opportunities to access assistive devices.

People with severe disabilities may be entitled to extensive support and assistance, under the LSS and LASS. These laws have made it possible for (a relatively small number of) people with severe disabilities to live an independent life. Some 13,700 people receive the state assistance allowance (under the LASS) and 5,200 people receive assistance under the LSS. However, this has come at a much higher cost than expected when the reform was planned. The national debate regarding disability policy is totally dominated by the increasing expenditure on the state assistance allowance.

Another area of controversy during recent years has been welfare crime and the overuse of benefits related to the state assistance allowance. Combatting welfare fraud is high on the political agenda. Certain measures have been taken, including the establishment of a new agency aimed at detecting financial fraud. The LSS has also been amended to prevent misuse of the payment for personal assistance by bogus or criminal actors.

Although no major reforms have been made in recent years to increase the support for people with disabilities, certain changes have been made to the cash benefits, and there are proposals to strengthen the rights to personal assistance.

1 Access to disability-specific income support

1.1 Disability-specific benefits/pensions available to working-age people

Sjukersättning (sickness compensation) (Section 1.1.1) and *Aktivitetsersättning* (activity compensation) (Section 1.1.2) (only for those below 30) are both disability insurance schemes based on previous work history, importantly with a minimum guaranteed level. The *Hemvårdsbidrag* (attendance allowance) (Section 1.1.3) is a disability assistance scheme.

1.1.1 *Sjukersättning* (Sickness compensation)

a) Eligibility conditions

Disability-related qualifying criteria: This benefit is available to people who have an illness or disability that makes them unable, both currently and in the future, to work in any job that is available on the labour market¹. Thus, the qualifying criteria are based on reduced work capacity. The reduction should be expected to be long-term. The reduction in work capacity can be assessed as 25%, 50%, 75% or 100%. The severity of the disability also interacts with age, as younger people need to have a more severe reduction in work capacity (see further details below under "Age"). In the assessment of work capacity, the individual's stated diagnosis, and additional needs to engage in certain activities, are compared with all available jobs on the labour market – not only the job(s) the individual has previous experience of or training for. The benefit is only available when all suitable rehabilitation measures have been carried out but have not improved work capacity (Socialförsäkringsbalken, SFS no. 2010:110).

Age: People aged 19-64 are eligible for this benefit. Those aged 19-29 must have a completely reduced work capacity (100%) to be eligible. People aged 19-29 with partially reduced work capacity may be entitled to *Aktivitetsersättning* (activity compensation) (see Section 1.1.2). People aged 30-64 do not need to have full disability, but their work capacity should be reduced by 25% or more.

Nationality and/or residency: There is no requirement for Swedish citizenship. The main criterion is that the applicant must have been insured in Sweden at the time when the disability arose. To be insured, a person must live or work in Sweden². In certain cases, however, it is possible to live abroad and still have Swedish insurance and thus be entitled to the benefit. For example, people who receive sickness compensation in Sweden but move abroad are still eligible^{3/4}.

Waiting period: There is no formal waiting period to apply for the compensation⁵. If the application is approved, it is granted from the moment the disability is certified (if the application is sent within three months from the medical certification of the disability).

¹ https://www.forsakringskassan.se/privatpers/sjuk/sjuk_minst_1_ar/sjukersattning

² These conditions apply to EU nationals. They also apply to non-EU nationals with a residency permit for at least a year.

³ The guarantee benefit (see paragraph c) can only be kept if the person moves to a country within the EU/EES, Switzerland or Canada.

⁴ Another example of where it is possible to receive the compensation when abroad is that people who live in an EU/EEA country (or a country that has an agreement with Sweden on social security) may be insured for the sickness compensation. If an application for sickness benefit or invalidity pension is made in an EU/EEA country, an application for Swedish sickness compensation will automatically be made if the person has lived or worked in Sweden (<https://www.forsakringskassan.se/english/sick/sick-for-one-year-or-longer/sickness-compensation/sickness-compensation-in-sweden>).

⁵ However, the applicant needs to wait for the National Social Insurance Agency to assess the application, which in April 2022 was taking around five months.

Contributory history: To receive the guaranteed level of compensation, no contributory history is required. People who have worked receive a higher benefit, based on previous earnings.

Level of financial resources: Not an eligibility criterion for this benefit.

Other: None.

Gaps/obstacles: People with disabilities may face obstacles in receiving compensation because of the disability-related qualifying criteria. The disability is not only medically assessed but also considered in relation to the labour market, which makes the definition of the labour market central (further discussed in paragraph b, under "Critical analysis"). Moreover, the age limit of 65 creates a gap in respect of older people with disabilities. There are also other benefits, such as the car allowance, which have the same discriminatory age limit (see Section 3, on assistive technology and devices, for a description of the car allowance).

b) Disability assessment framework

Type of assessment: Medically based assessment of disability, and functional capacity assessment.

Responsible authorities: The National Social Insurance Agency (*Försäkringskassan*) is the authority responsible for this benefit.

Method: Documentary evidence. Based on a medical certificate, the National Social Insurance Agency makes an assessment of the person's work capacity.

Supporting evidence: A medical doctor (or other healthcare staff) writes a medical certificate in which the person's medical diagnosis is described, as well as how the individual's ability to engage in certain activities is limited. In the instructions for healthcare staff, it is stated that they should clearly distinguish between the patients' own reports of their condition and the results of the medical examination⁶.

Assessor: Medical doctors and/or other healthcare staff, and a civil servant or case-handler (with a wide range of training backgrounds) at the National Social Insurance Agency. The case-handler can get support from a medical insurance advisor to assess the information in the medical certificate.

Decision-maker: The National Social Insurance Agency.

Critical analysis: A recent inquiry, commissioned by the government to review several social insurance benefits, highlighted a problem with how work capacity is assessed against the labour market (SOU 2021:69). In this assessment, all jobs in the labour market are considered, including sheltered jobs and jobs with a wage subsidy – even though such jobs may not be available. This creates a danger of over-estimating the actual possibility for people to support themselves through work (which the National Social Insurance Agency has also called attention to, in a letter to the government in 2017).

The very strict use of this all-encompassing definition of the labour market can hit certain groups hard. The government inquiry especially highlighted the situation for people aged 60 or over. Because age is not taken into consideration in the assessment, apart from the broad age groups mentioned above, some older people may not be able to find a job but are still denied sickness compensation – and thereby forced to collect their old-age pension at a lower age, resulting in a lower pension. The inquiry report therefore suggested that, in the assessment of people aged 60 or over, the labour

⁶ <https://www.forsakringskassan.se/halso-och-sjukvarden/sjukdom-och-skada/utlatande-for-sjukersattning>

market definition should only include jobs that the person has previous experience of, thereby facilitating their right to sickness compensation (SOU 2021:69).

c) Benefit entitlements

Level of the benefit: The levels of compensation are based on the person's age, previous work history and assessed work capacity. If the applicant has previously worked, they receive a sum corresponding to 64.7% of their average income during the last few years, up to a ceiling. How many years are taken into account varies depending on their age at the time when the disability arose, but varies between three to eight years⁷. The maximum (gross) amount paid is 19,531 SEK (~€1,953) per month.

If the applicant has never worked, they receive a basic (guaranteed) benefit, which increases step-wise with age between 19 and 30. Those aged 19 get 9,982 SEK (~€998) per month and those aged 30-64 get 11,190 SEK (~€1,119) per month⁸.

The applicant's work capacity is assessed as 25%, 50%, 75% or 100% disability. They receive a concomitant percentage of the benefit: 25% if the work capacity is assessed to be reduced by 25%, etc.

Duration of the benefit: The duration is indefinite, but the assessment is renewed every third year. If the beneficiary is 60 or over, the assessment is not renewed, as the benefit can only be received up to age 65 (Socialförsäkringsbalken, SFS no 2010:110).

Interaction with other income or other related benefits: Sickness compensation is the main social protection cash benefit for people with disabilities. How much compensation people receive may, however, vary (25%, 50%, 75%, or 100%), depending on how much the applicant's work capacity is reduced according to the assessment. The interaction between sickness compensation and income from work depends on whether the person receives partial or full sickness compensation. People who receive 100% sickness compensation have a completely reduced work capacity and do not receive income from work.

People who have sickness compensation may also be entitled to *bostadstillägg* (housing supplements). People with full sickness compensation may also get their study loans waived⁹. It is possible to receive unemployment insurance at the same time as receiving sickness compensation, but only if the sickness compensation level is 25% or 50%. People with higher levels of sickness compensation are not entitled to unemployment insurance. People may receive the *Tjänstepension* (statutory contributory pension) (which it is possible to withdraw from age 62) and still receive sickness compensation.

Sickness compensation also interacts with the sick pay benefit, which is intended for shorter periods of sickness or disability. A problem with the relationship between these two benefits, highlighted by the government inquiry (SOU 2021:69), is different definitions of the scope of the labour market; an all-encompassing definition is used for sickness compensation (see more above, paragraph b), whereas the definition used for the sick pay benefit is more relaxed. As a consequence, a large number of people remain on the sick pay benefit, even though their work capacity can be considered to

⁷ There are two rules: the "main" rule and the "alternative" rule. The main rule applies to people aged 30-64. The three highest income years during a period of five to eight years (before the year that the disability arose) are used to calculate the average income. For people aged 31-46, the last eight years are used. It increases step-wise until age 53-56, when the last five years are used. The alternative rule applies to people who are under 30. The two highest income years during the three years before the disability arose are used to calculate the average income.

⁸ https://www.forsakringskassan.se/privatpers/sjuk/sjuk_minst_1_ar/sjukersattning

⁹ <https://www.csn.se/betala-tillbaka/betala-tillbaka-studielan/avskrivning-av-studielan.html>

be reduced in the long-term, and there are no potential rehabilitation measures left to use.

Adequacy issues: The above-mentioned inquiry (SOU 2021:69) also highlighted that both the number and share of people who receive sickness compensation have declined since 2008, although no major changes have been made to the regulations. The inquiry showed that new grants have fallen sharply since 2015, and the refusal rate rose from 43% in 2014 to 70% in 2019. The main explanation for this development is, according to the inquiry, that the National Social Insurance Agency has tightened its interpretation of the regulations since 2015¹⁰.

Another issue is that an increasing proportion of beneficiaries only receive the basic guaranteed benefit. Between 2006 and 2020, the proportion increased from 10% to 27% among women, and from 16% to 42% among men. There are clear age differences in this respect, since older people have had time to work and are therefore entitled to a higher income-related benefit level. In 2020, more than 98% of those aged 19 received the guaranteed benefit, whereas the figure for the 60-64 age group was 10% for women and 14% for men (National Social Insurance Agency, 2021). Moreover, the role of work history in determining the compensation level is also to the disadvantage of people with a history of disability, if they have previously been prevented from working or had problems getting a foothold in the labour market.

1.1.2 Aktivitetsersättning (Activity compensation)

a) Eligibility conditions

Disability-related qualifying criteria: Work capacity reduced by at least 25%. The assessment of work capacity follows the same procedure as when people aged 30-64 apply for sickness compensation: that is, the National Social Insurance Agency assesses whether the person's work capacity is reduced by 100%, 75%, 50% or 25%.

Age: This compensation is available for people aged 19-29¹¹.

Nationality and/or residency: A person must be insured in Sweden (live or work in Sweden¹²) to be eligible. In certain cases, it is possible to live abroad and still have Swedish insurance and thus be entitled to the compensation.

Waiting period: None (i.e. it is granted from the moment the disability is certified, if the application is sent within three months from the medical certification of the disability).

Contributory history: In line with the sickness compensation, no contributory history is required to receive the guaranteed level of activity compensation. People who have worked receive a higher benefit, based on previous earnings.

¹⁰ It is not entirely clear in what particular aspects the interpretations of the regulations have become stricter. According to the National Social Insurance Agency, the application of the regulations has become more accurate in relation to the existing regulations. Explanations for this change are many, but the National Social Insurance Agency has pointed out that the definitions of the concepts "long-term" (concerning the reduction of the applicant's work capacity) and "labour market" are somewhat vague in the regulations for sickness compensation, which leads to variability in the interpretations (National Social Insurance Agency, PM 2018:6). In a report from 2018, the Swedish National Audit Office gives support to the view that the National Social Insurance Agency is not being too strict in their assessments in relation to the existing law, but instead that it may have been too generous during previous years.

¹¹ The activity compensation was created to prevent young people from being on long-term sick leave. It is similar to sickness compensation, but with the major difference that it is aimed at young people and that there is a time limit of one to three years (see also paragraph c). The time limit is designed to fully utilise the young person's opportunities to develop and work.

¹² These conditions apply to EU nationals. They also apply to non-EU nationals with a residency permit for at least a year.

Level of financial resources: This is not an eligibility criterion for the compensation.

Other: The person should not be able to work for at least a year (because of the illness or disability). In line with sickness compensation, this should be the case for any available job in the labour market.

People under 30 may also receive activity compensation if, because of their disability, they need a longer period than normal to complete grade school or upper secondary school¹³.

Gaps/obstacles: The disability-related qualifying criterion may represent an obstacle since it is defined as reduced work capacity. As discussed above in relation to sickness compensation, a person's sickness or disability is assessed in relation to an all-encompassing definition of the labour market, which may lead to a situation where people with significant disabilities are denied the compensation.

Young people who are denied activity compensation face the risk of beginning their adult years in a financially very vulnerable situation. A recently published report (ISF, 2021:2) showed that, among young people who were denied activity compensation, around 40% had to turn to social assistance at least once during the following three years.

b) Disability assessment framework

Type of assessment: Medically based assessment of disability, and functional capacity assessment.

Responsible authorities: The National Social Insurance Agency.

Method: Documentary evidence. Based on a medical certificate, the National Social Insurance Agency makes an assessment of the person's work capacity.

Supporting evidence: A medical certificate, including the same components as the certificate needed for sickness compensation¹⁴.

Assessor: Medical doctors and/or other healthcare staff, and a civil servant or case-handler (with a wide range of training backgrounds) at the National Social Insurance Agency. The case-handler can get support from a medical insurance advisor to assess the information in the medical certificate.

Decision-maker: The National Social Insurance Agency.

Critical analysis: The strict and all-encompassing definition of the labour market mentioned above (in relation to sickness compensation) applies to activity compensation as well, along with the problems the definition may lead to (SOU 2021:69).

c) Benefit entitlements

Level of the benefit: The levels of compensation are the same as for sickness compensation – between 9,982 SEK (~€998) and 19,531 SEK (~€1,953), depending on work history.

Duration of the benefit: The compensation is granted for a limited time of one to three years. It is, however, possible to receive the benefit for more than one such time period,

¹³ https://www.forsakringskassan.se/privatpers/funktionsnedsattning/aktivitetsersattning-och-sjukersattning/aktivitetsersattning_forlangd_skolgang

¹⁴ <https://www.forsakringskassan.se/halso-och-sjukvarden/sjukdom-och-skada/utlatande-for-aktivitetsersattning>

after a new assessment¹⁵. During the time a person receives activity compensation, they can get help and support to start working¹⁶.

Interactions with other income or other related benefits: People receiving activity compensation may also be entitled to housing supplements. It is possible to receive unemployment insurance at the same time as receiving activity compensation, but only if the level of sickness compensation is 25% or 50%. People with higher levels of activity compensation are not entitled to unemployment insurance.

Adequacy issues: As for sickness compensation, there is a variability over time in the refusal rates, even though the regulations have remained the same. Although there has not been the same increase in refusal rates for activity compensation, the recent government inquiry (SOU 2021:69) pointed out that such variability over time is problematic from the perspective of legal certainty and may also negatively affect people's trust in the National Social Insurance Agency.

People who receive activity compensation are entitled to engage in different types of activities, such as daytime activities, workplace learning, sports, education, or organisational activities. This is an important aspect of the activity compensation, with the aim to enhance the young person's opportunities to work and develop. The planning and monitoring of the activities is done by the National Social Insurance Agency. The aforementioned government inquiry (SOU 2021:69) also evaluated the real opportunities for such activities. The inquiry report put forward several criticisms. It concluded that the support to start working that recipients of activity compensation are entitled to is in practice rather scarce. Moreover, according to the inquiry, there is a lack of suitable activities for this group of people; the National Social Insurance Agency has a limited capacity to co-ordinate different activities; and there is inadequate follow-up of the activities, both on an individual and aggregate level. In addition, the inquiry suggested that the regulations concerning work and education for people receiving activity compensation are complicated and inflexible. The regulations are unclear concerning which activities people can engage in, and to what extent, and still keep their right to activity compensation (this also applies to sickness compensation). For example, it is not possible to receive a partial benefit when studying part time. Uncertainties and strict rules may keep people from engaging in educational and other activities (SOU 2021:69).

1.1.3 Hemvårdsbidrag (Attendance allowance)

a) Eligibility conditions

The attendance allowance is aimed at informal care. It is a net cash payment given to people with disabilities, which they are to use as payment to the care-giver. The care-giver can be a family member or other person who is close to the person receiving care.

Disability-related qualifying criteria: Need for support to carry out daily activities and/or need for care.

Age: Not a criterion.

Nationality and/or residency: The allowance is managed at municipal level, and it is also optional for the municipalities to provide the allowance. Thus, only people who live in a municipality that provides it are eligible.

Waiting period: None (i.e. it is granted from the moment the disability is certified).

¹⁵ In 2019, 45% of those aged 30 who exited activity compensation were transferred to sickness compensation (SOU, 2021:69).

¹⁶ <https://www.forsakringskassan.se/privatpers/funktionsnedsattning/aktivitetsersattning-och-sjukersattning/aktivitetsersattning-vid-nedsatt-arbetsformaga>

Contributory history: No contributory history is required.

Level of financial resources: Not a criterion.

Other: The allowance is aimed at informal carers who provide help with personal care. The help given should be extensive, of the kind that would be carried out by the home-help services if there was no informal carer who was able or willing to carry out the tasks (NBHW, 2021).

Gaps/obstacles: It is optional for a municipality to provide the allowance; and if they do, they are also free to decide on eligibility criteria and levels of payment.

b) Disability assessment framework

Type of assessment: This is a cash benefit provided under the Social Services Act (SoL), and eligibility for attendance allowance is tested against the criteria for support according to the SoL. If the application for support is due to disability (people can also apply due to old age), eligibility is based on a medical assessment of the disability and an assessment of the person's need for support.

Responsible authorities: The municipality.

Method: Both documentary evidence and personal interaction are used.

Supporting evidence: A medical diagnosis and an assessed need for support. These include a medical note or letter from a doctor who treats the applicant, self-assessment, and evidence from someone who is closely familiar with the applicant's living situation.

Assessor: Medical doctor(s) and a social worker at the municipality.

Decision-maker: The municipality.

Critical analysis: As mentioned above, the attendance allowance is optional for the municipalities, and eligibility criteria may vary. This means that, in addition to the general assessment procedure described above, municipalities may give more or less weight to certain aspects. For example, in Stockholm, the municipality with the largest number of inhabitants, the benefit is granted if the care results in considerable excess work for the care-giver. In Gothenburg, the second largest municipality in terms of inhabitants, there is not the same emphasis on care burden, but one criterion is that the carer needs to be found suitable for the task.

c) Benefit entitlements

Level of the benefit: The allowance is set in relation to the extent of care needs. In Stockholm municipality, the most populated municipality, the benefit ranges from 1,208 SEK (~€121) to 4,830 SEK (~€483) per month.

Duration of the benefit: There is no limit on the duration of the allowance, but the assessments are followed up regularly.

Interactions with other income or other related benefits: The allowance can be combined with home-help services.

Adequacy issues: Data on municipal cash benefits ceased to be part of Swedish official statistics in 2006. Figures from 2006 showed that 5,300 people received the attendance allowance. This was already a small number then, and the general understanding nowadays is that the number of people receiving the allowance is falling, and that this benefit plays quite a residual role (Schön and Johansson, 2016; NBHW, 2021). The fall has been described as a development that is in accordance with the general Swedish principle that services in kind are prioritised over cash benefits (Schön and Johansson, 2016).

1.2 Disability-specific old-age pension schemes

There are no disability-specific old-age pension schemes. People with disabilities are covered by the general old-age pension schemes, described below in Section 2.1.

1.3 Income support aimed at covering disability-related healthcare and housing expenses

1.3.1 Healthcare

1.3.1.1 *Merkostnadsersättning* (Additional cost allowance)

a) Brief description

The *Merkostnadsersättning* (additional cost allowance) is a benefit for people with disabilities, targeted at expenses that arise because of disability (expenses considered to be above the average for people of the same age with no disability). It is not exclusively aimed at healthcare expenses, but such expenses are included. The allowance covers a broad range of areas, including expenses for special diets, travel, assistive devices (if the municipality cannot provide them¹⁷) and home-help services. The additional cost allowance may also cover certain expenses for housing that are not covered by other benefits, for example a move to different housing if additional space is needed to fit in healthcare equipment or assistive devices¹⁸.

The benefit only covers expenses that the person has paid out of their own pocket. Healthcare expenses are only covered up to the national ceiling for patient fees and medication, the "high-cost protection" (*Högekostnadsskydd*), after which they are covered by the high-cost protection¹⁹.

People are eligible for the additional cost allowance if they fulfil all the following criteria: i) they have a disability or functional impairment that is expected to persist for at least a year (and which arose before age 65); ii) they have disability-related expenses equal to at least 12,075 SEK (~€1,208) per year; iii) they are insured in Sweden; and iv) they are at least 18 and do not have a parent who is legally obliged to provide for them (this can be extended to 21 for those attending secondary/high school).

b) Main gaps/obstacles

As stated above, one of the eligibility criteria is that the disability must have arisen before the person reached 65. Even though people may continue to receive this benefit after 65 if their disability arose earlier, there may be an obstacle for people whose disabilities arose later. This may be a problem for the older population, as disabilities – at least when defined as having limited capacity to perform daily activities – clearly increase with age (Fors *et al.*, 2022). Assistive devices may be provided by the

¹⁷ The municipalities and regions are obliged to offer assistive devices to those who need them. However, it is up to the municipalities and regions to divide the responsibility between them and to decide upon regulations and fees. There are thus local variations in which assistive devices are available and paid for by the municipality: <https://www.1177.se/Stockholm/behandling--hjalpmedel/hjalpmedel/sa-far-du-ett-hjalpmedel/att-fa-ett-hjalpmedel/>.

¹⁸ <https://www.forsakringskassan.se/privatpers/funktionsnedsattning/merkostnadsersattning-for-vuxna>

¹⁹ The high-cost protection means that there is an upper limit for how much people need to pay out of their own pocket. For out-patient care, a patient pays a maximum of 1,200 SEK (~€120) during a 12-month period. The high-cost protection for medication includes certain prescribed medicines, and a person pays a maximum of 2,400 SEK (~€240) for medications that are included in this scheme during a 12-month period. Costs for hospital stays and travel expenses due to illness or childbirth are also included in the high-cost protection. <https://www.1177.se/Stockholm/sa-fungerar-varden/kostnader-och-ersattningar/patientavgifter/>. Brief description in English: <https://ec.europa.eu/social/main.jsp?catId=1130&langId=en&intPageId=4809>.

municipality, and older people are therefore to some extent financially supported in relation to their disability. However, older people may be disadvantaged regarding other features of the additional cost allowance, such as support for medication costs.

c) Main adequacy challenges

This allowance was introduced in 2019 and replaced the *Handikappersättning* (disability allowance). The reform is further described in Section 4.2.1. An evaluation in 2020 suggested that the National Social Insurance Agency had not been given sufficient time and resources to manage the transition to the new allowance, which resulted in, for example, long waiting times for applicants and gaps in payments (ISF, 2020:5). In late 2020, the government commissioned the Swedish Social Insurance Inspectorate (*Inspektionen för socialförsäkringen* – ISF) to evaluate the reform with regards to clarity, predictability, and benefit levels²⁰. The evaluation was due to be presented in September 2022.

1.3.2 Housing

1.3.2.1 Bostadsanpassningsbidrag (Housing adaptation grant)

a) Brief description

The housing adaptation grant is aimed at supporting people with disabilities to live independently in their own homes. It is nationally available and not means-tested. The grant is applied for and decided on at a municipal level. It is available for most types of disabilities, such as physical impairments, visual disability, intellectual impairments, or allergies. The disability should be permanent, or at least long-term²¹. The housing adaptations can be of varying kinds, such as replacing a bathtub with a shower cabin, arranging a ramp at the house entrance, or enhanced lighting in the kitchen. Several criteria should be met for the benefit to be granted, one being that there must be a clear link between the disability and the adaptation, and that the adaptation can be considered necessary to make the home fit for purpose²². The grant is given for adapting the “fixed function” of a home (i.e. things that are not brought along when moving). Grants for housing adaptations are mainly for a person’s primary residence (and not their second homes). It is also possible to receive a grant for an adaptation in a “periodic home” – the home of someone who has a long-term care responsibility for the person with disabilities, and in which the person with disabilities lives on a regular basis.

To apply, a person needs a certificate from an occupational therapist, medical doctor or other care personnel, with an assessment of the disability and the person’s need for housing adaptations²³.

There are no financial limits in the Law on Housing Adaptation Grants (2018:222), but the municipality decides on the sum that can be granted based on an assessment of reasonable costs. The municipality assesses the application, which may involve a home visit. As an alternative to a cash benefit, the grant may also be in the form of a

²⁰ <https://www.regeringen.se/regeringsuppdrag/2020/11/uppdrag-att-utvardera-reformen-om-reformerade-stod-till-personer-med-funktionsnedsattning/>

²¹ The law does not specify the exact duration of what should be considered long-term. According to the National Board of Housing, Building and Planning, a medical certificate from a medical doctor or other healthcare staff could give guidance:

<https://www.boverket.se/sv/babhandboken/bostadsanpassningsbidrag/villkor-for-bostadsanpassningsbidrag/nodvandiga-atgarder/>.

²² <https://www.boverket.se/sv/babhandboken/for-dig-som-soker/vad-ar-bostadsanpassningsbidrag/>

²³ <https://www.1177.se/Stockholm/behandling--hjalpmedel/hjalpmedel/sa-far-du-ett-hjalpmedel/bostadsanpassning/>

commitment made by the municipality to carry out the housing adaptation and the necessary maintenance/repairs.

b) Main gaps/obstacles

Although the grant is nationally available, the process of handling applications and how the regulations are interpreted varies between municipalities, which may affect a person's chances of receiving it. In a report by the National Board of Housing, Building and Planning (NBHBP, 2020) it was stated that costs related to the benefit varied greatly between municipalities, but that these variations could be partly explained by a higher share of older people living in the different municipalities (grants are more often given to older people). In 2019, 46% of the grants were given to people aged 70-84 and 29% to people aged 85 and over (NBHBP, 2020).

The above-mentioned report also criticised the management of the grant in many municipalities, a problem that has been highlighted for several years. Although some improvements have been made since the new Law on Housing Adaptation Grants (SFS no 2018:222) came into effect, remaining management weaknesses include the fact that written decisions were being made after the home adaptation had been carried out (NBHBP, 2020).

Moreover, the report (NBHBP, 2020) showed that the number of applications for housing adaptation grants, and the related municipal expenditure, fell between 2015 and 2019. In 2021, the government therefore commissioned the National Board of Housing, Building and Planning to conduct an inquiry into the grant, to see if there were obstacles for people with disabilities to receive it (Government Offices of Sweden, 2021a). The inquiry is due to be presented in February 2023.

c) Main adequacy challenges

There are no major studies on adequacy challenges regarding the housing adaptation grant in its new form (SFS no 2018:222). The above-mentioned inquiry may cover such issues.

2 Access to some key general social protection cash benefits

2.1 Old-age benefits

The Swedish pension system consists of several components. The statutory contributory pension; the *Garantipension* (statutory guarantee pension); and supplementary pension schemes by economic sector (based on collective bargaining between the trade unions and the employers' confederations). Moreover, there is a system of personal pension schemes with private insurance providers. In this section, we describe the statutory pensions.

The statutory contributory pension has two parts: the statutory contributory pension, which is a pay-as-you-go pension (income pension), and a statutory funded pension, which is fully funded (premium pension). Each year, the pension contribution is 16% of taxed earnings for the income pension, and 2.5% of earnings for the premium pension. The earnings taxed include salaries but also social benefits such as sickness compensation and unemployment insurance. Retirement is flexible from 62 (there is a proposal to increase it to 63 in 2023), and can be postponed indefinitely²⁴.

²⁴ There is a legal right to work until 68, and in 2023 this will be increased to 69. If people want to, they can postpone their retirement even longer, provided they make an agreement with their employer. However, this possibility depends on the collective agreements between the trade unions and the employers' confederations (<https://www.pensionsmyndigheten.se/ga-i-pension/planera-din-pension/hojd-pensionsalder>).

The statutory guarantee pension is the second component of the Swedish public pension system. It provides a basic pension for people with no, or a very low, statutory contributory pension. People who have turned 65 are eligible, but there is a proposal to increase this to 66 in 2023. The benefit level does not increase if the pension age is postponed beyond 65.

2.1.1 Tjänstepension (Statutory contributory pension)

a) Eligibility conditions

The eligibility criteria are the same for people with and without disabilities.

b) Additional amount/compensation included and adequacy issues

There is no additional compensation within this pension benefit for people with disabilities.

c) Gaps/obstacles

Since this pension scheme is based on lifetime earnings, people will get a higher pension the longer they postpone retirement, and people with lower earnings will receive lower pensions. This may be to the disadvantage of people with disabilities, who may have had lower incomes because of unemployment, part-time work or early retirement (Gustafsson and Danermark, 2017). Although benefits such as sickness compensation are taxed and thus contribute to people's pensions, the incomes from such benefits are considerably lower than average earnings. Sickness compensation is a maximum of 19,531 SEK (~€1,953) per month, whereas in 2020 the average salary in Sweden was 36,100 SEK (~€3,610) and the median salary was 32,400 (~€3,240)²⁵.

2.1.2 Garantipension (Statutory guarantee pension)

a) Eligibility conditions

The eligibility criteria are the same for people with and without disabilities.

b) Additional amount/compensation included and adequacy issues

There is no additional compensation for people with disabilities. However, income-tested housing supplements are part of the pension system²⁶, which can be an important source of income for older people with low incomes, which may often be the case for people with disabilities. *Äldreförsörjningsstöd* (income-tested old-age income support) also exists²⁷. This benefit is an extra support for people aged 65 and over who receive all pension benefits they are entitled to but still do not reach a decent standard of living, as specified in the national standards (Socialförsäkringsbalken, 2010:110, chapter 74).

c) Gaps/obstacles

Being dependent solely on the guaranteed pension, with no additional compensation for disability-related expenses, makes older people with disabilities financially vulnerable. As pointed out in a report, several laws regarding support and services for people with disabilities have an upper age limit at 65 (Gustafsson and Danermark, 2017). For example, if a disability arises after a person has turned 65, they are not entitled to the additional cost allowance. Also, after age 65 people are no longer eligible for sickness compensation and have to depend on their pension.

²⁵ <https://www.scb.se/hitta-statistik/sverige-i-siffror/utbildning-jobb-och-pengar/>

²⁶ <https://www.pensionsmyndigheten.se/for-pensionarer/ekonomiskt-stod/fakta-om-bostadstillagg>

²⁷ <https://www.pensionsmyndigheten.se/for-pensionarer/ekonomiskt-stod/ansok-om-aldreforsorjningsstod>

2.2 Unemployment benefits

The Swedish unemployment benefit system consists of two tiers. The first tier is an earnings-related benefit, and the second is a universal flat-rate benefit.

2.2.1 *Arbetslöshetsförsäkring – Inkomstbortfallsförsäkring (Income-related unemployment benefit)*

a) Eligibility conditions

The eligibility conditions are the same for people with and without disabilities. There is, however, an “activity requirement” that is important to point out. People must be able to work for at least three hours per day (and on average 17 hours per week), be registered as part-time or full-time unemployed with the Public Employment Service (*Arbetsförmedlingen*), be actively seeking work, and immediately accept available job offers (SFS 1997:238).

b) Additional amount/compensation included and adequacy issues

The level of the benefit is the same for people with and without disabilities.

c) Gaps/obstacles

Disability advocacy groups have highlighted that the activity requirement of both the *Arbetslöshetsförsäkring – Inkomstbortfallsförsäkring* (income-related unemployment benefit) and the basic unemployment benefit (described below, Section 2.2.2) can be hard to meet for people with disabilities. People with an estimated work capacity of 25% cannot meet the criteria of being able to work three hours per day. It may also be difficult to reach the required work history (Gustafsson and Danermark, 2017).

2.2.2 *Arbetslöshetsförsäkring – Grundförsäkring (Basic unemployment insurance)*

a) Eligibility conditions

The eligibility conditions are the same for people with and without disabilities. The same activity requirements for the contributory benefit also apply to the basic benefit.

b) Additional amount/compensation included and adequacy issues

The level of the benefit is the same for people with and without disabilities.

c) Gaps/obstacles

The problems with activity requirements and previous work history mentioned above in Section 2.2.1 also apply to the *Arbetslöshetsförsäkring – Grundförsäkring* (basic unemployment insurance).

2.3 Guaranteed minimum income schemes and other social assistance benefits

2.3.1 *Försörjningsstöd (Social assistance)*

a) Eligibility conditions

The eligibility conditions are the same for people with and without disabilities.

b) Additional amount/compensation included and adequacy issues

There is no additional compensation for people with disabilities. However, the benefit does cover medication costs.

c) Gaps/obstacles

Försörjningsstöd (social assistance) is the last resort for financial assistance and is administered and paid at the municipal level. This benefit is aimed at short-term

financial assistance, and not designed for people with disabilities. Eligibility conditions include being ready to take up employment, similar to the requirement for unemployment insurance. Those applying for support should carry out several administrative tasks, such as recording the jobs they apply for. Such eligibility conditions may be particularly difficult to meet for people with intellectual disabilities. Although the social assistance benefit is not designed for people with disabilities, people may have to rely on it if they are denied disability-specific benefits but are not well enough to find work. In 2019, there was some media coverage of this issue, showing that the number of people with disabilities receiving social assistance had increased between 2017 and 2019 (SVT, 2019; 2021). A report by the National Board of Health and Welfare showed differences in the take-up of social assistance among people with disabilities, according to which law they were covered by – the Act Concerning Support and Services for People with Certain Functional Disabilities (LSS) or the SoL (see Section 3 below for a description of these). In 2018, around 2% of those with services under the LSS, and around 11% of those with services under the SoL, received social assistance for at least 10 months (NBHW, 2020).

3 Provision of assistive technology and personal assistance

3.1 Assistive technology and devices

The Swedish regions and municipalities are obliged to provide assistive devices for people with disabilities who need them. The regions and municipalities make an agreement on how to divide the responsibility between them and which rules and fees should be in place. Therefore, there are some variations in the availability of different devices, the costs and where to apply for a device. Some regions and municipalities provide devices for free, and some charge a user fee. The provision of devices is based on a needs assessment carried out by a prescriber at the responsible authority. All people with disabilities who live, work or reside in Sweden have the same right to apply for assistive devices as Swedish citizens.

Assistive devices can be prescribed by different professional groups, such as: occupational therapists; physiotherapists; speech therapists; audiologists; and registered nurses²⁸. Some examples of the different types of available assistive devices are: hearing aids and other ear devices; visual aids; incontinence protection; cognitive support aids; communication support aids; mobility and walking aids; devices in the home such as bedroom and bathroom aids; breathing aids and respiratory devices; diabetes care equipment; and orthopaedic technology and aids²⁹.

Based on a report from the early 2010s, it has been pointed out that the variations in fees between municipalities and regions create unequal opportunities to access assistive devices across the country (Gustafsson and Danermark, 2017). This inequality was also pointed out in the most recent report by the National Board of Health and Welfare on the availability of assistive devices (NBHW, 2016).

A person with disability who needs assistive devices to manage at work can apply for an allowance from the National Social Insurance Agency. There are also work-life related allowances that can be obtained through the healthcare services, the municipality, the employer, or the Public Employment Service. Some people may need benefits from both the National Social Insurance Agency and other actors³⁰.

²⁸ <https://www.norden.org/en/info-norden/allowance-assistive-devices-sweden>;
<https://www.forsakringskassan.se/english/for-employers/employee-with-a-disability/allowance-for-assistive-devices>

²⁹ <https://www.1177.se/Stockholm/behandling--hjalpmedel/hjalpmedel/sa-far-du-ett-hjalpmedel/att-fa-ett-hjalpmedel/>

³⁰ <https://www.norden.org/en/info-norden/allowance-assistive-devices-sweden>

A person with a permanent disability can apply for a car allowance from the National Social Insurance Agency. The conditions for this benefit are: i) there must be a disability that causes major difficulties in getting around or travelling by public transport; ii) the difficulties must be permanent; and iii) the person must be insured in Sweden. To obtain a car allowance, a person needs to belong to one of four groups, as follows.

- 1) A person under 65 who is dependent on a car for work, attending occupational rehabilitation with activity compensation or rehabilitation allowance, or attending vocational training. The work, rehabilitation, or training must be expected to continue for at least six months.
- 2) A person under 65 who previously obtained a car allowance, and after that has received sickness compensation or activity compensation.
- 3) A person aged 18-49 who drives the car by themselves.
- 4) A person who has a child under 18 who lives at home, and who needs a car to move about with the child, and drives the car by themselves.

The car allowance consists of three separate benefits: i) basic allowance; ii) purchase allowance; and iii) adaptation allowance. The basic allowance is a maximum of SEK 30,000 (~€3,000). The purchase allowance, which is income-tested, is a maximum of SEK 40,000 (~€4,000). The basic and purchase allowances can be complemented by the adaptation allowance if the car needs special adaptations and/or equipment. The adaptation allowance is a maximum of SEK 60,000 (~€6,000)³¹.

3.2 Personal assistance

Services provided since the Social Services Act

All people in Sweden with a need for care and support, irrespective of age and type of disabilities, are covered by the SoL (SFS 2001:453). The SoL stipulates that the 290 municipalities have the ultimate responsibility for ensuring that all their residents obtain the support and help they need. The municipalities have a special responsibility to ensure that people with physical, mental, or intellectual functional disabilities can live their lives in accordance with Swedish disability policy. Anyone who needs help or support in day-to-day existence has the right to claim assistance if "the needs cannot be met in any other way" (Social Services Act, 2001, chapter 4, §1).

There are no national regulations on eligibility. As eligibility criteria, service levels, and the range of services provided are decided locally by the municipalities, there are substantial variations in the provision of support.

Services provided under the Act Concerning Support and Services for People with Certain Functional Impairments and the Assistance Allowance Act

Under certain conditions, people with severe disabilities can be covered by the LSS (SFS 1993:387); and in certain cases also by the Assistance Allowance Act (1993:389) (LASS) (if the requirement for personal assistance for basic needs exceeds 20 hours per week). The LSS and LASS were vital parts of the disability reform and came into force in 1994. The LSS is designed to provide people with severe disabilities with greater opportunities to live independent lives, and to ensure that they have equal living conditions and enjoy full participation in society. Within the LSS, there are 10 measures for individualised special support and service, aimed at providing this group with good living conditions in the community, rather than institutional care (Clevnert and Johansson, 2007; Schön and Johansson, 2016; Swedish Institute, 2022).

³¹ <https://www.forsakringskassan.se/english/for-employers/employee-with-a-disability/allowance-for-assistive-devices>

The LSS differs from other Swedish health and social care legislation, in that it is an entitlement law that sets out the rights of people covered by it, and what requirements they can place on municipalities or the state. Other laws in the area regulate the responsibilities of different care-providers against the individual. In addition, the LSS is a "plus law", which means that it does not restrict support and services regulated by other laws.

To be entitled to services, a person must belong to one of three groups defined in Section 1 § 1-3 of the LSS, as follows.

1. People with intellectual disabilities, autism or conditions similar to autism.
2. People with significant and permanent intellectual disabilities following brain damage in adulthood. The injury must have occurred through physical violence or physical illness.
3. People with other severe and permanent physical or mental disabilities that are not due to normal ageing. The disabilities must be so severe that they cause significant difficulties in everyday life and an extensive need for support or services.

Among the 10 different services available under the LSS, one covers personal assistance. It is a central, and by far the costliest, part of the LSS. People may be entitled to personal assistance if they have major disabilities and an extensive need for support in their daily lives (i.e. support with basic needs, including breathing, personal hygiene, meals, clothing, and communicating, or other support that requires in-depth knowledge about the person). The municipality is financially responsible for those who need personal assistance for less than 20 hours a week. A person who needs assistance for more than 20 hours a week may be entitled to receive the state assistance allowance via the National Social Insurance Agency. The right to this allowance is set out in the LASS (1993:389). The social insurance administration takes the decision regarding the allowance. The municipality is, however, still financially liable for the first 20 hours in such cases. Personal assistance must have been granted before the person reaches 65, and the number of hours of assistance cannot be increased after the person's 65th birthday. The services under the LSS are in principle free of charge to the user, with a few exceptions (e.g. a person who lives in housing with special services has to pay the rent for the flat, and costs for food and other personal expenses; but they will not pay for service and support from staff). According to Section 19 § of the LSS, only reasonable fees are allowed to be charged. The fees cannot exceed the municipality's actual costs for the services and the individual must have enough money to cover personal expenses such as food, healthcare, leisure and holidays (National Board of Health and Welfare, 2009).

The main obstacle regarding personal assistance is the raised eligibility criteria due to changes in case law and interpretations of the legislation, especially how basic needs are interpreted, which has resulted in much stricter needs assessments by the National Social Insurance Agency (described in more detail in Section 4.1). Due to the raised eligibility threshold and increased number of withdrawals from the state assistance allowance, many people do now receive their assistance from the municipalities instead. Consequently, some of the costs have also been transferred from the state to the municipalities (National Board of Health and Welfare, 2021). Issues regarding problems and lack of clarity caused by the divided responsibility between the municipalities and the National Social Insurance Agency have been addressed in a government investigation (Dir. 2021:76), described below (Section 4.2.4).

Another kind of support available to people with disabilities is that they can have a family member employed by the municipality as their carer (*Anhöriganställning*). The family member is paid based on the number of hours of help the person with disabilities needs, according to a needs assessment. In all, there were some 13,700 people eligible for the state assistance allowance (under the LASS) in 2021 (National Social Insurance Agency, 2021), but the percentage being cared for by a family member is not known.

4 National debates, reforms and recommendations

4.1 National debates

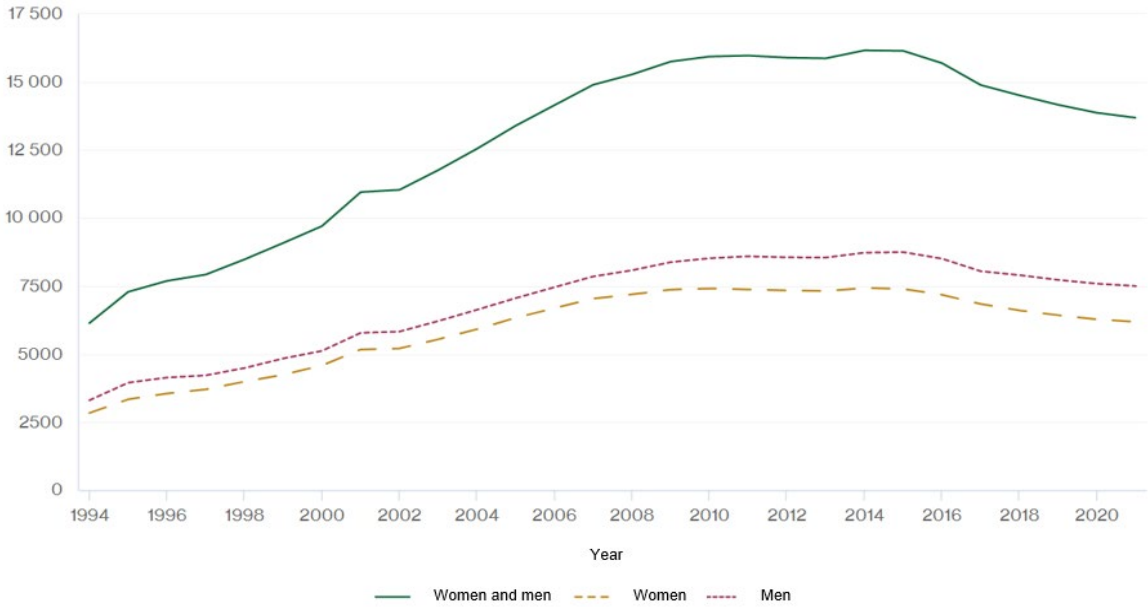
4.1.1 Increasing expenditure on attendance allowance

The national debate regarding disability policy has, since the 1994 disability reform, been dominated by the expenditure on personal assistance. In the early 1990s there was a lively discussion around whether the reform was sufficiently funded or not. In more recent years the focus of the debate has been on what is often referred to as the “cost explosion” and “rampant expenditure” on the state assistance allowance. Many recipients are concerned that their right to support and services could be severely weakened by politicians’ ambitions to save money, and that as a result fewer people would be entitled to the allowance.

An important element of the construction of the LSS was individuals’ right to self-determination, to shape their own life and to live independently. The idea was inspired by the American independent living movement, and the reform can be considered as a part of the “freedom of choice reform revolution” proclaimed by the conservative government in the early 1990s. In an overview article, an economist and political expert/advisor for the government during the planning of the LSS said that the state assistance allowance was launched without extensive impact analyses (Kallin, 2018). The government bill was poorly substantiated, and it assumed, without reference to investigations or analyses, that the need for personal assistance would amount to an average of 40 hours per week for 7,000 eligible users. The annual cost was estimated at SEK 3.3 billion (~€330 million) (in today’s values). According to the National Social Insurance Agency’s expenditure forecast, the cost of the state assistance allowance for 2022 is estimated to SEK 25 billion (~€2.5 billion). This excludes municipalities’ spending on personal assistance under the LSS, which was SEK 12 billion (~€1.2 billion) in 2021 (National Board of Health and Welfare (2021)). Thus, the state assistance allowance is one of the most expensive social insurance benefits, even though it applies to one of the smallest benefit groups.

The development of spending on the state assistance allowance is mainly due to three factors: 1) the number of recipients of the allowance; 2) the number of hours of assistance per recipient; and 3) the allowance per hour (the level of hourly allowance is determined annually by the government).

Figure 1: Number of people receiving state assistance allowance under the Assistance Allowance Act, by sex, 1994-2020.



Source: Swedish Social Insurance Agency (2021).

The number of people receiving the allowance under the LASS increased steadily until 2009 and has since then stabilised (Figure 1). Since 2015, the number of people receiving the allowance has fallen, which can be primarily explained by a lower inflow of people to the insurance. This is due to changes in case law, with stricter assessments by the National Social Insurance Agency. The share of rejections increased from 35% in 2007 to 80% in 2017. In 2021, 13,700 people were receiving the allowance under the LASS. The total number of hours granted has, however, continued to increase. The average number of hours per person per week in 2021 was 131.2 (National Social Insurance Agency, 2021).

4.1.2 Welfare fraud and abuse

In recent years, increased attention has been paid to welfare crime, fraud and overuse of benefits related to the state assistance allowance. Swedish welfare services are publicly funded, but they are increasingly provided by the private sector. Sweden has one of the world's most unregulated welfare sectors, and the highest share across Europe of private for-profit companies providing welfare services (Schön, 2019; Swedish Tax Agency, 2012). The lack of regulations and low level of control, combined with the push for freedom of establishment for private providers, may have contributed to an increase in the number of bogus and organised criminal companies as assistance-providers.

The fight against welfare fraud is a controversial topic and is high on the political agenda. A concern is that this will have a negative impact on the legitimacy of the state assistance allowance, and eventually lead to stricter eligibility criteria, requirements, and controls, which will have negative repercussions for those who really need personal assistance.

The government's strategic report "Personal assistance: Analysis of a quasi-market and its crime" (2018), on how personal assistance is systematically exploited by organised crime, concluded that the market for assistance-providers was unregulated until 2011, which led to the establishment of many bogus providers and the defrauding of public money. Since 2013, the number of private assistance-providers has fallen, and the market is today dominated by a few dominant actors. The assistance market is today by far the most privatised welfare service in Sweden.

There is, however, no consensus on how much of the costs of the state assistance allowance are due to fraud, over-utilisation and the involvement of organised criminal companies. Assuming that crime and over-exploitation are not grossly under-estimated, only a small part of the sharp cost development can be explained by it. The main explanation is still the increase in the number of hours of personal assistance granted for personal needs other than basic ones (i.e. breathing, personal hygiene, meals, clothing, communicating or other support that requires in-depth knowledge about the person).

The Swedish government has prioritised the fight against the increasingly sophisticated and deliberate abuse of the welfare system. In June 2020, a government investigation (SOU, 2020:35) proposed that a new government agency, the Payment Control Agency, should be established. In September 2021, the government presented an action plan against welfare fraud. Combatting welfare fraud and abuse is of utmost importance for the public's confidence in the welfare system. The new agency will detect and prevent irregularities in payments from the state welfare system. According to the proposal, the agency is planned to start operating in 2024 (Dir. 2022:8).

4.2 Recent reforms and reforms currently in the pipeline

4.2.1 Reform of certain financial support

In 2019, the additional cost allowance replaced the disability allowance, as part of a larger reform which also included the *Vårdbidrag* (care allowance). The aim of the reform was, among other things, to remedy the lack of clarity identified in the previous legislation, such as ambiguities in the definitions of core concepts (Government bill 2017/18:190). This was thought to create clearer rules and increase uniformity in the assessments. Another change was that the additional cost allowance would be exclusively focused on additional costs

caused by disability, excluding those caused by support needs covered by the disability allowance, since the needs for support are provided by the municipalities and regions. In late 2020, the government commissioned the ISF to evaluate the reform. The evaluation of the additional cost allowance was due to be presented in September 2022³².

4.2.2 Amendment of the LSS and LASS regarding payment of the state assistance allowance

In June 2021, the government presented a white paper on amendments to the LSS (1993:387) and social insurance code (2010:110). The amendments provide the National Social Insurance Agency and the municipalities with legal support for refusing payment of the state assistance allowance, where the assistance comes from a provider not accredited in accordance with Section 23 § of the LSS. The amendments mean that a gap in the legislation has been filled, making it more difficult for bogus and criminal actors to exploit people entitled to personal assistance (Government bill 2020/21:205).

Lena Hallengren, Minister of Health and Social Affairs, has said: *“The purpose of the amendments in LSS is to reduce cheating in personal assistance so that those who run an assistance company really have the competence and experience required to obtain a permit. Ultimately, it is a security issue for those who are dependent on personal assistance.”* (Government Offices of Sweden, 2021b).

The National Social Insurance Agency and the municipalities now have an obligation to inform the Health and Social Care Inspectorate when personal assistance is provided without accreditation. The inspectorate has been given clearer powers to request information for the discharge of their supervisory duties (Government bill, 2020/21:205). The amendments came into force on 1 November 2021.

4.2.3 Strengthened right to personal assistance

In May 2021, the “inquiry on strengthened assistance” presented its final report on how to strengthen the right to personal assistance for people with disabilities (SOU 2021:37).

The inquiry was designed to generate proposals on how to strengthen the right to assistance for supervision and self-care as well as increased legal certainty for children. The inquiry submitted proposals in several areas, such as changes in basic needs. These changes give a stronger right to personal assistance for people who, because of recent changes in case law, cannot receive these services. Moreover, rules are proposed for healthcare that clarify the responsibility for caring for people with extensive disabilities. Through the proposals, these people will have the opportunity for cohesive support without losing their personal assistance (SOU 2021:37). In the budget proposal for 2022, the government stated that it aimed to make reforms based on the inquiry, for example to strengthen the right to the type of personal assistance called “supervision”³³.

4.2.4 State responsibility for personal assistance

In September 2021, the government appointed an inquiry chair with instructions to analyse and propose how personal assistance should be organised with the state as the responsible authority. Since the LSS reform was implemented in 1994, the division of responsibilities between the municipalities and National Social Insurance Agency has been a problem and created a lack of clarity (Dir. 2021:76).

³² <https://www.regeringen.se/regeringsuppdrag/2020/11/uppdrag-att-utvardera-reformen-om-reformerade-stod-till-personer-med-funktionsnedsattning/>.

³³ <https://www.regeringen.se/pressmeddelanden/2021/09/regeringen-foreslar-atgarder-for-ett-starkare-samhalle-for-alla/>

The ambition of the proposal for state responsibility is an appropriate and effective regulation that creates stable long-term conditions for services of good quality, characterised by high legal certainty and subject to follow-up and control. The inquiry should also consider proposals for alternative solutions to state responsibility. The investigation will be presented in March 2023. If the entire responsibility for personal assistance is transferred to the state it will be a major reform of the LSS.

4.3 Good practice and recommendations on how to tackle gaps and obstacles

Swedish disability policy, legislation and other service measures are designed to “*achieve equitable living conditions and full participation in a diverse society for people with disabilities*” (Swedish Institute, 2022). Another ambition is to help and support individuals and to promote maximum independence from the family. The Swedish welfare state aims to provide support and financial security throughout the life course, from the cradle to the grave.

These aims and ambitions have in many respects been fulfilled. The LSS and the state assistance allowance have, for example, made it possible for (a relatively small number of) people with severe disabilities to live an independent life in the community. Before the LSS came into force, these people were doomed to a life in institutions or to a life dependent on their families. However, as discussed above (Section 4.1), the reform came at a much higher cost than expected (Kallin, 2018), which eventually risks becoming a threat to the its sustainability.

The Swedish welfare model, with extensive public programmes for people with disabilities, has been shown to be a successful way to relieve families of the burden of care obligations. A positive effect of these programmes is that they have allowed many people to stay in the labour market³⁴. Similarly, the legislative measures in the SoL and LSS have been effective in unburdening families and carers of people with disabilities³⁵.

There is a need for comprehensive evaluations of sustainability issues, legitimacy and trust in connection with various welfare programmes. Due to a lack of official statistics and research, it is difficult to assess the effects of several measures targeting people with disabilities. We therefore recommend that official national statistics be improved, to better monitor the living conditions of people with disabilities. We call for both a strengthening of data-collection mechanisms and an increased scope of the data that are collected.

The political focus has for many years been on the rising costs of the state assistance allowance, but there have not been any serious political discussions on whether personal assistance is too expensive. What should the costs for personal assistance be compared with, and what would a reasonable cost be? What consequences would drastic changes in the state assistance allowance have for people with disabilities and their families? There is virtually no knowledge on what alternatives to personal assistance would cost (Kallin, 2018). Therefore, we recommend a transparent discussion of policy priorities, to support sustainable legislation in this area.

³⁴ The high percentage of women in the labour force (80%) is evidently an effect of generous welfare programmes.

³⁵ For a further discussion, see ESPN Thematic Report on Work-life balance measures: Schön and Johansson (2016).

References

- Clevnert, U. and Johansson, L. (2007). Personal assistance in Sweden. *Journal of Aging & Social Policy*, 19(3), 65-80.
- Dir. 2022:8. (2022). Inrättande av Utbetalningsmyndigheten [Establishment of the Payment Control Agency]. Available at: <https://www.regeringen.se/492e6a/contentassets/165bda08173144f5a5572a7c43f42bfb/inrattande-av-utbetalningsmyndigheten-dir.-20228.pdf>.
- Dir. 2021:76. (2021). Statligt huvudmannaskap för personlig assistans [State responsibility for personal assistance]. Available at: <https://www.regeringen.se/4a79e8/contentassets/fed57814e2bd4e9ab1f2bc0e00cf798c/dir--2021-76.pdf>.
- Fors, S., Illinca, S., Jull, J., Kadi, S., Phillips, S.P., Rodrigues, R., Vafaei, A., Zolyomi, E., & Rehnberg, J. (2022). Cohort-specific disability trajectories among older women and men in Europe 2004–2017. *European Journal of Ageing* Available at: <https://doi.org/10.1007/s10433-022-00684-4>.
- Government bill 2017/18:190. (2018). Reformerade stöd till personer med funktionsnedsättning [Reformed support to people with disabilities]. Stockholm: Ministry of Health and Social Affairs.
- Government bill 2020/21:205. (2021). Utbetalning av ersättning för personlig assistans endast vid tillstånd [Payment of allowance for personal assistance only with permission]. Stockholm: Ministry of Health and Social Affairs.
- Government Offices of Sweden (2018). Promemoria S2018/00301/FST. Personlig assistans – Analys av en kvasimarknad och dess brottslighet. [Personal Assistance - Analysis of a quasi-market and its crime] <https://www.regeringen.se/48eba8/contentassets/c6601ca30ff54c99bb6d61d213237043/personlig-assistans--analys-av-en-kvasimarknad-och-dess-brottslighet.pdf>
- Government Offices of Sweden (2021a). Uppdrag om bostadsanpassning. Dnr: S2021/06045. Available at: <https://www.regeringen.se/regeringsuppdrag/2021/08/uppdrag-om-bostadsanpassningsbidrag/>. (Retrieved 16 February 2022.)
- Government Offices of Sweden (2021b). Utbetalning av ersättning för personlig assistans utan tillstånd förbjuds. Pressmeddelande: publicerat 1 oktober 2021 [Payment of allowance for personal assistance without permit is prohibited. Press Release: published 1 October 2021].
- Gustafsson, J. (2019). ANED Country report on disability assessment, Sweden.
- Gustafsson, J. and Danermark, B. (2017). ANED country report on Social Protection and Article 28, Sweden.
- ISF (2021:2) [Inspektionen för Socialförsäkringen / The Swedish Social Insurance Inspectorate]. Avslag på ansökan om aktivitetstillsättning [Refusal of application for activity support]. Gothenburg: Inspektionen för Socialförsäkringen.
- ISF (2020:5) [Inspektionen för Socialförsäkringen / The Swedish Social Insurance Inspectorate]. Införandet av omvårdnadsbidrag och merkostnadsersättning [The implementation of child carer's allowance and additional cost allowance]. Gothenburg: Inspektionen för Socialförsäkringen.
- Kallin, M. (2018). Assistansen: Ett slukhål i statsbudgeten [Assistance allowance: A loophole in the state budget]. Kvartal: 23 July 2018. Available at: <https://kvartal.se/artiklar/assistansersattningen-ett-slukhal-i-statsbudgeten/>.
- National Social Insurance Agency (2021). Socialförsäkringen i siffror 2021 [The social protection system in figures 2021]. Stockholm: Försäkringskassan.

- National Social Insurance Agency (2017). Remissvar på "En sjukförsäkring med prevention, rehabilitering och trygghet (SOU 2021:69) samt Promemoria – Stärkt trygghet vid långvarigt nedsatt arbetsförmåga" [Missive to the inquiry A sickness compensation with prevention, rehabilitation and security (SOU 2021:69) and Memorandum "Strengthened security for long-term impaired work capacity"]. Dnr FK 2021/014988 and Dnr FK 2021/017234.
- National Social Insurance Agency (2017:3). Sjukersättning – Rättslig kvalitetsuppföljning [Sickness compensation – Legal quality assessment]. Available at: <https://www.forsakringskassan.se/wps/wcm/connect/dc31fafa-c26a-4ccc-9a80-7a5d09672002/rattslig-uppfoljning-2017-3.pdf?MOD=AJPERES&CVID=>.
- NBHP – National Board of Housing, Building and Planning (2020). Bostadsanpassningsbidragen 2019. Rapport 2020:19.
- NBHW, National Board of Health and Welfare (2021). Insatser och stöd till personer med funktionsnedsättning. Lägesrapport 2021 [Services and support to people with disabilities. Status report 2021]. Stockholm: National Board of Health and Welfare.
- NBHW, National Board of Health and Welfare (2020). Insatser och stöd till personer med funktionsnedsättning. Lägesrapport 2020 [Services and support to people with disabilities. Status report 2020]. Stockholm: National Board of Health and Welfare.
- NBHW, National Board of Health and Welfare (2016). Hjälpmedel i kommuner och landsting. En nationell kartläggning av regler, avgifter, tillgång och förskrivning [Assistive devices in the municipalities and regions. A national overview of regulations, fees, availability and prescriptions]. Stockholm: National Board of Health and Welfare.
- NBHW, National Board of Health and Welfare (2009). Swedish disability policy. Service and care for people with functional impairments. Retrieved from Stockholm: National Board of Health and Welfare.
- Schön, P. (2019). Sweden: No profit cap in the Swedish welfare sector. ESPN Flash Report 2019/32. European Social Policy Network (ESPN), Brussels: European Commission.
- Schön, P. and Johansson, L. (2016). ESPN Thematic report on work-life balance measures for people of working age with dependent relatives. Sweden 2016. European Social Policy Network (ESPN). Brussels: European Commission.
- SFS no. 2018:222 om bostadsanpassningsbidrag. Available at: https://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/lag-2018222-om-bostadsanpassningsbidrag_sfs-2018-222.
- SFS no. 1997:238 om arbetslöshetsförsäkring. Available at: https://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/lag-1997238-om-arbetsloshetsforsakring_sfs-1997-238.
- Skatteverket [The Swedish Tax Agency] (2012). Skatteplanering i företag inom välfärdssektorn. Slutrapport [Tax planning in companies in the welfare sector. Final report].
- Socialförsäkringsbalken, 2010:110. Available at: [Socialförsäkringsbalk \(2010:110\) Svensk författningssamling 2010:2010:110 t.o.m. SFS 2021:1268 – Riksdagen](#).
- SOU 2020:35. (2020). Kontroll för ökad tilltro – en ny myndighet för att förebygga, förhindra och upptäcka felaktiga utbetalningar från välfärdssystemen. Betänkande av Utredningen om samordning av statliga utbetalningar från välfärdssystemen [Control for increased trust – a new authority to prevent and detect incorrect payments from welfare systems. Final report from the Inquiry on coordination of government payments from welfare systems]. Stockholm: Statens offentliga utredningar. Available at: <https://data.riksdagen.se/fil/D8DAD045-B831-4D5C-8C51-FE19308774E1>.

- SOU 2021:37. (2021). Stärkt rätt till personlig assistans. Ökad rättssäkerhet för barn, fler grundläggande behov och tryggare sjukvårdande insatser. Betänkande av utredningen om stärkt assistans [Strengthen the right to personal assistance. Increased legal certainty for children, more basic needs and safer healthcare interventions. Final report from the Inquiry on Strengthened Assistance]. Stockholm: Statens offentliga utredningar. Available at: https://www.regeringen.se/49bd9f/contentassets/6a4b04e7bc584315931893a15690e99/sou-2021_37_komplett.pdf.
- SOU 2021:69. (2021). En sjukförsäkring med prevention, rehabilitering och trygghet. Betänkande av utredningen om sjuk- och aktivitetsersättningen samt förmåner vid rehabilitering [A sickness compensation with prevention, rehabilitation and security. Final report from the Inquiry on the Sickness and Activity Compensation, and Rehabilitation Benefits]. Stockholm: Statens offentliga utredningar.
- SVT (2021). Available at: <https://www.svt.se/nyheter/lokalt/ost/nya-siffror-visar-funktionsnedsatta-tvingas-till-socialen>.
- SVT (2019). Available at: https://www.svt.se/nyheter/lokalt/ost/nya-siffror-hundratals-funktionsnedsatta-tvingas-soka-socialbidrag?fbclid=IwAR1E1VbiRatvQvr8gyh-bqInHwq0IFNuZF0NUHg2ItN58BFcZDn_mLPolkc.
- Swedish Institute. (2022). Full participation in society is the top goal in Sweden's disability policy. Available at: <https://sweden.se/life/equality/disability-policy>.
- Swedish National Audit Office (2018:9). Nekad sjuk- och aktivitetsersättning – effekter på inkomst och hälsa [Denied sickness and activity compensation – effects on income and health]. Stockholm: Swedish National Audit Office.

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