



Sweden Fact Sheet on Social Care & Support Services Sector for Persons with Disabilities

Part of a series of Country Fact Sheets available on the EASPD website

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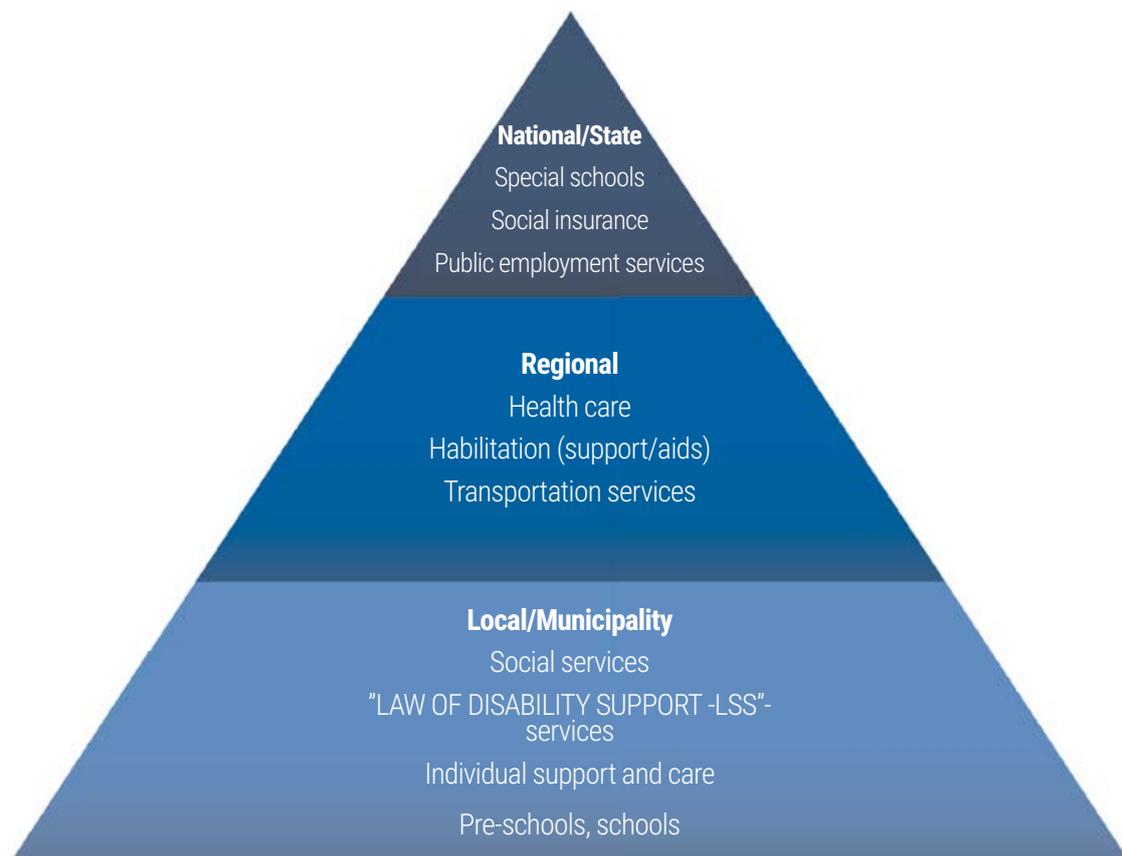
SUBSECTORS OF SOCIAL CARE & SUPPORT SERVICES AND THEIR CHARACTERISTICS

Social support and services for people with disabilities are available on national, regional and municipal level. The different levels provide different kind of support and services, based on four main acts: Social Services Act, Health Services Act, Education Act, and the Law concerning support and services for persons with certain disabilities (henceforth Law on Disability Support – LSS). In Sweden the principle of free choice of care is applied, which means that citizens have the right to seek health care services wherever they want in the country. The free choice of care applies to both publicly financed and private care, if the private care provider has an agreement with the region.

On the national level, different kinds of economic support, such as disability-related benefits and income supplements as well as direct financing for different services, such as for personal assistance allowances, is provided by the governmental social insurance agency. Special schools for students with hearing-, language-, or/and visual impairments, and any of these in combination with intellectual disabilities, are also governed at the national level, and provided by the Special Education School Authority.

Meanwhile, healthcare and medical services are governed on the regional level and include habilitation measures and assistive devices, financed by the national income tax system and free for children and fee-based for adults, up to a maximum rate, and provided by mostly public but also private providers, the latter more common in urban areas. For healthcare services, the national care guarantee applies, which determines the maximum waiting time for services. If specialist care is required, a visit must be offered within 90 days and additional treatment should be started within 90 days. In years around the time of developing this factsheet in 2019, however, media has reported on long waiting times in specialized health care, which are responsible for disability-related health services and assistive devices but the waiting times vary between different regions and between different kind of services.

Figure 1. Support and services on national, regional and municipal level in Sweden



Source: author



The municipalities primarily provides services like in-kind care support measures as provisioned in the Social Services Act and the the Law on Disability Support - LSS. The LSS is explicitly directed at people with certain disabilities – intellectual disabilities, autism spectrum diagnoses, brain injuries and/or severe permanent physical or mental functional impairments that cause considerable difficulties in daily life, and regulates entitlement to ten different support measures and services. The Social Services Act regulates disability-related services for persons with physical, cognitive and/or psychiatric disabilities. Persons with disabilities can apply for services to the municipality, where the social services or equivalent administration is responsible for decisions on support and service. The services are free of charge and financed by the income tax system.

Municipalities are also responsible for the running of local preschools and schools. There are special divisions in schools for students with disabilities, following a special curriculum (särskola) and various resource schools focusing on children with special needs.

Municipalities and regions are independent from the state and can choose different organizational solutions. The main organizational solutions are:

- municipal government care performed mainly by staff employed in the municipality, and
- private management - the municipality has the ultimate responsibility for the service, but the service is performed by other than the municipality, e.g. companies (incl. municipal companies), foundations or cooperatives, on behalf of and paid the municipality.

Since 2009, when the Freedom of Choice Act came into force, regions and municipalities have been able to offer a system where the individual has the right to choose the supplier to perform the service. Freedom of choice -systems are compulsory in preschool, school and primary care. In other areas (i.e. social services and other health care) it is optional for municipalities and regions to introduce it.

From 2010, the the freedom of choice also applies to the public employment service. Not all municipalities have introduced this system and the organization of services differ across the country.

Early Childhood Intervention

Support and services for children with disabilities are the responsibility of the state, the regions and the municipalities. The Social Insurance Agency (national level) is responsible for various types of financial support, which includes care allowances, allowances for additional expenses and financial support for personal assistance. The health care sector is responsible for medical support and disability-related services, such as habilitative support or assistive devices and the social services in the municipality are responsible for providing assistance to manage daily life according to the Law on Disability Support – LSS.

Children with disabilities, if assessed by a health care provider (such as a GP or nurse in the primary health care services) to have more extensive needs for care, are referred to specialized health care for rehabilitation and habilitation. Child habilitation is a specialist resource intended to provide support for children and adolescents with diagnoses in the autism spectrum, acquired brain injury, hearing loss, mobility disabilities, intellectual disabilities, visual impairment or certain medical disabilities. The support includes, among other things, medical interventions, adaptation of the home environment, aids, sign interpreting services and support to promote motor, linguistic, psychological and educational development. Habilitation services are often organized as a unit, within the regional health care services, with access to doctors, nurses, physiotherapists, occupational therapists, speech therapists and psychotherapists. Collaboration often takes place with other bodies in society, such as pre-schools, social services and the social insurance agency.

Social services at the municipal level include short-term relief services¹ and personal assistance on the basis of a needs assessment by an official in the social services. Children with disabilities may be entitled to personal assistance according to the Law on Disability Support - LSS. For children requiring less than 20 hours support need a week, the municipality is responsible for the personal assistance, while the Social insurance agency is responsible for assistance exceeding 20 hours

¹The short-term relief service means a service that temporarily takes over the care of the child from its guardians.



per week. For young children, the need for extra supervision and care due to the disability should form the basis for the assessment of the right to personal assistance. Providers of these services could be both public or private or a mix of both, depending on how the municipality chooses to organize the support and services to persons with disabilities. The support and services provided are free of charge.

If the child is assessed to have greater support needs than can be provided in their home, the municipalities can provide accommodation with special service for children with disabilities, according to the Law on Disability Support – LSS. It is the municipalities that are responsible for accommodation with special support, that can be provided by public or private providers. The accommodation should resemble ordinary homes as much as possible, with few children in each dwelling. The municipality is responsible for ensuring that medical personnel are available if the child's condition requires it.

Children with disabilities have the right to preschool and the Education Act states that support should be given to children in need of special support in preschool. The support should primarily be given in a mainstream preschool setting, which means that the educational activities in preschool must be adapted so that all children in the group can take part. In practice this often means that a special assistant is hired by the school who, together with the school health team (nurse, physician, psychologist, and special education teachers) support the child in the mainstream settings. In some larger municipalities, there are preschools especially adapted for children with disabilities, such as preschools with sign language departments that serve both children with deafness and children with hearing loss. The School Inspectorate reports that there are no reliable figures on how many children are in need of special support in preschool.² The reports show that approximately one in five children in preschool is in need of special support and that approximately 4% of the children in pre-school have a disability. Children who, due to their disability or for other special reasons, are unable to attend the mainstream schools can be admitted to specialized schools. There are eight specialized schools run by the Special education school authority which also run pre-school classes.

Municipalities are responsible for both preschools and schools, except the specialized schools that fall under state responsibility. Preschools are most often publicly governed (80 %) but there are no statistics on the proportion of children with disabilities in public/private/non-profit preschools. Preschools are mainly financed through income taxes but unlike the rest of the Swedish school system, a fee applies. The fee is based on the family's income up to a maximum rate and applies to children with or without disabilities alike.

Education Support

Children are in the compulsory school system from age 6-16 and upper secondary education is optional. Education in Sweden is free of charge and financed by the income tax system. Each individual has the right to choose which school to attend and both public and private schools receive a grant from the municipality for each student under the so-called "school voucher system". It is most common for students to attend compulsory education in a municipal, publicly governed school. During the academic year 2018/19, approximately 25% of the students in upper secondary education attended a private school. In compulsory school, the proportion was 15%. There are no statistics available of the proportion of students with disabilities in public vs private mainstream schools, as the schools are not allowed to collect statistics on health status or disability, only on students in need of special support. Being in need of special support in school does not have to correspond with having a disability. The Education Act states that support should be given to students with difficulties in learning, and the Act applies to both municipal and private schools. No diagnosis or disability recognition is required to receive support in preschool or school, it is based on individual needs. The school health team (nurse, physician, psychologist, and special education teacher) assesses individual needs and advise on what support is needed. The support should be given promptly and to the extent that the student needs, but the School Inspectorate reports show that many schools do not live up to this commitment. This seems especially to be the case for students with disabilities, whether in public or private schools.

²The school inspectorate. Children in need of special support in preschool. Available at: <https://www.skolinspektionen.se/globalassets/publikationssok/granskningsrapporter/kvalitetsgranskningar/2017/forskolans-arbete-med-barn-i-behov-av-sarskilt-stod/forskolans-arbete-med-barn-i-behov-av-sarskilt-stod-2017.pdf>



There are two different school options for students with disabilities. The mainstream school system provides different kinds of support to students in need of special support in education, where students with intellectual disabilities can read a special curriculum (in Swedish "särskola"), there are specialized units for students with intellectual disabilities. Based on an assessment on educational, psychological, medical and social needs, the educational unit in the municipality determines whether the child can attend compulsory school for students with intellectual disabilities. During the academic year 2018/19, 10,529 students attended "särskolan" in the compulsory school system, which corresponds to approximately 1% of all students in mainstream compulsory education. In upper secondary education, 5,469 students attended "särskolan" which corresponds to 1,7% of all students in mainstream compulsory education. Most often these students attend a publicly governed compulsory school (94% in compulsory education/ 97 % in upper secondary education). Children or adolescents who, due to their disability or for other special reasons, are unable to attend the mainstream school system can be admitted to special needs schools (specialskola). There are eight special schools run by the special education school authority, state-financed, and which receive students from all over the country. The target group for the different schools is students with deafness or hearing impairment, children with hearing impairment and intellectual disabilities, children with deaf blindness, children with visual impairment combined with other disabilities and children with severe speech disabilities. The special school consists of five regional schools (with a total of 400 students 2018/2019) and four national schools (with a total of 259 students 2018/2019). However, many students with disabilities, such as hearing loss, visual impairment or speech disabilities, receive their education in the mainstream school system, in the municipality where the family is living. There are no statistics available on students with disabilities in the mainstream schools as the schools are not allowed to collect statistics about disability.

It is unusual for children to use personal assistance according to the Law on Disability Support - LSS in preschool and school. Both the mainstream schools and special schools have a far-reaching responsibility for the children during school hours and can provide assistants with the task of providing personal support to students who need it, but the support can also be provided as a resource that is linked to a class or school. The headmaster of the school makes a decision whether an assistant should be attached to a particular student or act as a resource for a group of students. Any child staying in preschool or school is not entitled to assistance compensation during these hours.

Adult education consists of two school types: municipal adult education and special education for adults (also provided by the municipalities). Adults with intellectual disabilities or acquired brain injury may apply for special education for adults (in Swedish "sär vux").

School-age children and adolescents are entitled to organized leisure activities (in Swedish "fritidsverksamhet") up to the age of 12. The municipality is responsible for leisure activities, which are often run by the school. A fee applies to leisure activities, based on the family's income up to a maximum rate. For children and adolescents over the age of 12 with extensive disabilities who, for various reasons, cannot manage themselves before or after the school day or during school holidays, may apply for short-term supervision. Short-term supervision is offered before and after the end of the school and full days during school holidays and is available from the age of 12 (beforehand this service is given in the mainstream school system) until the student has left upper secondary school. The services are provided by the social services in the municipality, under the Law on Disability Support – LSS, and the municipal social service unit assesses needs of the adolescent and makes decisions on short-term supervision.

Employment Support

The Public Employment Service is responsible for the active labour market schemes and labour market policies concerning people with disabilities. In the years leading up to 2019, the public employment services have increased the range of digital services available to job-seekers and reliance on private providers for active labour market schemes. Job-seekers may have the right to choose the provider (public/private/non-profit) to perform these schemes, in line with the Freedom of Choice Act (described in the introductory section), but services and providers available differ on the local level. Private and non-profit providers are hired through regional and local procurement processes for provision of the specific measures, paid for by the Public Employment Service. Social enterprises are also contracted by the Public Employment Service and



there are about 350 work-integrating social enterprises in Sweden that employ about 6,200 people. It is common for these enterprises to have agreements with the Public Employment Service, where they sell services that include work training to people with disabilities.

Within the Public Employment Service, job seekers with recognized disabilities, assessed by a special unit for jobseekers with disabilities, are offered a range of measures and employment support whether through mainstream schemes and/or those especially targeting people with disabilities. Schemes targeting people with disabilities and their scope (approximate figures) in 2018 are:

- wage subsidies - 100,000 persons;
- special support to start a business - 700 persons;
- sheltered employment at Samhall, (a state-owned company providing sheltered employment to persons with disabilities) - 25,000 persons;
- sheltered employment in the public sector -3,000 persons;
- special introductory and follow-up support, (a supported employment programme targeting job-seekers with disabilities - 10,000).

In addition job seekers with disabilities are eligible to receive work aids, additional support at the workplace, and interpreter services for persons with hearing disabilities. There are also a range of schemes especially targeting young job seekers with disabilities in which they can receive guidance, specialist support or customisation of the workplace at the transition from school to work (7,000 persons in 2018).

The Public Employment Service collaborates with the Social Insurance Agency to increase possibilities for employment for those who receive activity compensation ("disability pension" for persons 19-29 years) under the Social Insurance Code.

Labor market policy is a state responsibility, but the municipalities play a key role through various vocational support and services. This is especially for those groups who, for various reasons, need extra support to enter the labor market. The measures offered are often different types of job training and placements in municipal labor market units, sometimes in combination with targeted support for competitive jobs in the open labor market. However, there is a difference between municipalities in the types of support offered.

Day Care

Day care for adults with disabilities is mostly provided in the form of "daily activities" under the Law on Disability Support - LSS (eligibility criteria described in the introductory section) or the Social Services Act (physical, cognitive and/or psychiatric disability). Daily activities can be described as a form of sheltered workshop for adults with disabilities who are of working age but assessed, by the municipal social services, unable to be gainfully employed. Daily activities are provided by the municipal social services, and the providers can be both public or private. The private providers have procurement agreements with the municipal social services, who are responsible for the day care services. In 2018, some 37,800 persons had daily activities under the LSS and 5,340 persons according to Social Services Act. The municipalities decide themselves on the design of daily activities but such activities that resemble paid work are common, either at a sheltered workshop or at a placement in mainstream business, or social and leisure activities.

Living Support

There are several kinds of support that persons with disabilities can receive from society as different means of assistance for independent living. The most comprehensive support is personal assistance, which is provided under the Law on Disability Support - LSS. For persons with disabilities who are not the target group of the LSS, living support could be provided under the Social Services Act in the form of housing support. Other kinds of living support are provided by health care services (e.g assistive devices) and by the municipalities (e.g. housing grants). Persons with disabilities may also have access to a special transport service if they have difficulties moving on their own or traveling by public means of communication. Assistive devices used for living support are provided by the health care services, as described in the introductory section.



Personal assistance provided under the LSS (eligibility criteria described in the introductory section) can be granted to people with extensive disabilities who need support in their daily life. The municipality is responsible for providing assistance if the support needs are assessed to be less than 20 hours a week. The responsibility is carried out through various alternatives. The social services could provide assistance (publicly governed), or they can outsource the provision through procurement to private or non-profit organisations. If the individual's disability-related needs cover more than 20 hours a week, the individual may be entitled to personal assistance allowance (Swedish acronym LASS) from the Social Insurance Agency. In the years leading up to 2019, when this factsheet was drafted, personal assistance was provided to approximately 20,000 people yearly, of which approximately 16,000 have had personal assistance allowance (LASS) from the Social Insurance Agency. The purpose of the personal assistance allowance (LASS) is to provide monetary support for a person with disability to hire personal assistants and is regulated in separate legislation, the Assistance Benefits Act of 2010. The government sets a standard amount for personal assistance allowance (LASS) every year. There is no lower age limit for obtaining personal assistance allowance (LASS) and it is possible to continue receiving it after the age of 65 if it has been granted before that age. A person cannot obtain personal assistance allowance (LASS) if he/she lives in specially adapted housing, according to the Law on Disability Support – LSS.

The users may custom-design their services according to their individual needs and decide themselves when, how and by whom the services should be provided. The original idea of provision of personal assistance was that the user themselves should choose how the assistance is organized. Options include employing the assistants themselves, hiring assistants from the municipality or together with other beneficiaries form so-called user cooperatives which, in turn, employ assistants. Over time, the proportion of private providers has increased while the proportion of municipal providers has decreased. In december 2016, there were a total of 1,044 personal assistance providers, both private and public. In addition, more than 500 users arranged their own assistance, by employing assistants themselves.

Housing support provided under Social Services Act is a service-in-kind where persons with disabilities are given support in their own home, in the community and/or in contact with authorities. The municipal social services are responsible for the support and it is provided by municipal or private/non-profit providers procured by the municipality. In 2017, approximately 21,000 persons received housing support. Persons with disabilities may be entitled to a financial contribution to adjust their housing. The right to such grants is governed by the Housing Adaptation Grant (2018:222) and covers reasonable costs for the adjustment. The municipalities are responsible for the grant and the individual applies for a grant themselves, and local officials assess the need and decide on the grant. If the municipality has granted a housing adjustment grant, the applicant chooses a contractor and orders the work. If a housing adjustment grant has been granted as a municipal undertaking, the municipality becomes a contracting party with the contractor. Media has reported long waiting times for housing adjustments, but this varies across the country. An individual could pay for the measures needed privately and apply afterwards, but then risks the grant not covering the entire cost.

The Special Transport Service (in Swedish "färdtjänst") is regulated by the Travel Services Act. The municipal social services decide on the Special Transport Service after receiving an application. Persons with a disability that entails major difficulties in moving on their own or traveling by public means of communication are eligible for the service. The rules for how the service may be used vary in the country as does the fee for travel. The number of people with Special Transport Service permits is about 300,000 and in 2017 about 11MN trips with Special transport service were made.

Health care services and the municipalities are responsible for assistive devices for daily living. Eligibility is based on needs, assessed by healthcare professionals, and people with disabilities usually obtain their assistive devices via public health-or medical-care providers who procure a limited range of assistive devices/aids to prescribe. Some regions apply the principle of free choice of assistive devices, which means that the user himself receives a grant to buy an assistive device and is responsible for the purchase, handling and maintenance of the device, while other regions take responsibility for the the acquisition, handling and maintenance. However, work aids are the responsibility of the Public employment service and the Social insurance agency. The disability NGOs have been concerned with waiting times for obtaining assistive devices but no national data is available. The national care guarantee does not apply to assistive devices, with an exception for hearing aids but even so the national care guarantee has not been fulfilled and in the region of Örebro, for example, waiting times for hearing aids are reported to be 1,5 years in average.



Long-term Institutional Care and Respite Care

In line with the ambition that all people in Sweden should have the opportunity to live a life like others in society, the use of long-term institutional care has decreased and a review in 2008 noted that all long-term institutional care homes for people with disabilities had closed down. Institutional care has been replaced with residential care, in the form of special accommodation for adults with certain disabilities, provided under the Law on Disability Support - LSS (eligibility criteria described in the introductory section) as housing with special services or other specially adapted housing for adults with certain kinds of disabilities. In 2018, approximately 28,000 persons were living in some form of special accommodation. The municipality is responsible for arranging the special accommodation, which could be provided under municipal government or by private providers, procured by the municipalities. There are three different forms of special accommodation:

- Group housing, targeting individuals who has need for supervision and care 24 hours a day.
- Service housing, which consists of a number of apartments with access to a common service and a permanent staff group. The apartments are adapted to individual needs where the individual can receive support around the clock, in their own apartment.
- Other specially adapted housing, which means that the individual has an own apartment, adapted to the individual needs.

Special accommodation for children is provided by the social services in municipalities, under the Law on Disability Support – LSS, in family homes or in homes with special services for children or young people with disabilities. In 2017, 912 children were living in special accommodation under this scheme. The National Board of Health and Welfare reports show that special accommodation for children is sometimes granted when other support is withdrawn, such as personal assistance allowances (LASS).

Special accommodation under the Social Services Act, (eligibility criteria described in the introductory section) is provided to people with extensive care and supervision needs that extend over much of the day. Municipalities are responsible for arranging and financing the special accommodation service, and the providers can be public or private, procured by the municipality. In 2018 approximately 4,500 persons were granted special accommodation under this scheme.

Municipalities also provide short-term respite care for families with children with disabilities, as described in the section early childhood intervention.

Leisure and Social-Life Support

Persons with disabilities who need support to participate in social, leisure and cultural activities can apply for a contact person or attendant service. These efforts are granted according to the Law on Disability Support - LSS or the Social Services Act and provided by municipalities directly or by private providers, procured by the municipalities.

Many municipalities have different leisure activities aimed at children, adolescents or adults with disabilities, often in the form of camps in the summer and during school holidays. The municipal LSS units often arrange these leisure activities, which are publicly financed and governed. Camps and other leisure activities may also be arranged by NGOs, such as disability organizations.

Persons who, due to a disability, need an assistant to carry out holiday travel has the opportunity to seek reimbursement for the additional costs this entails. Compensation for such additional costs may be granted as assistance under Social Services Act or as temporary extended assistance under the LSS.

All newspapers published in Sweden can apply to become an audio newspaper. Newspapers that publish in an accessible format for people with reading disabilities receive financial support and technical support from the Swedish Agency for Accessible Media. There are also opportunities for people with disabilities to borrow audio books at no charge at the municipal libraries.



FUTURE TRENDS

A great share of the service and support for people with disabilities is a municipal responsibility, which means that the trends look different depending on whether the municipality is big or small or whether it is placed in an urban or rural area. In general, the municipalities describe a difficult financial situation, some more than others, where many report insufficient funds to sustain to the extent of services that persons with disabilities are entitled to. There is an on-going discussion about who should carry the financial responsibility for the support, a discussion that has been active for many years without any change in the division of responsibility.

In 2016, the government decided on a review of the Law on Disability Support - LSS and personal assistance allowance (LASS) with the aim of creating a long-term sustainable financial development and more cost-effective support and services under the LSS. It was presented in 2018 and shows that the costs for services, and especially personal assistance allowance, have increased over a longer period of time. The review proposes that a new law on support and service for certain persons with disabilities should replace the current law. During the period from January 2022 to December 2024, those with a decision on personal assistance or assistance allowance shall reapply for such support but how it will be decided and how it will affect the extent of support and service for the individual is still unclear at the time of drafting this factsheet at the end of 2019. Since 2016, concerns have been raised, from persons with disabilities and professionals, about how the eligibility criteria for the LSS have been interpreted, as assessments of disability have become increasingly restrictive, both at the national level by the Social Insurance Agency and at the local level by the municipalities. However, the statistics do not justify this concern as the number of people who receive services under the LSS (approximately 74,000 persons) have increased by 2% between 2017 and 2018. There was also a marginal reduction of 0.2% of the number of persons with disabilities entitled to services under the law during the same period. However, with regard to the Personal Assistance Allowance (LASS), the number of persons with granted personal assistance allowance is clearly decreasing while the average numbers of hours per week of assistance are increasing slightly.

As a result of the municipalities' financial situation, where personal assistance is seen as an expensive service, and the reduction in the number of people with granted personal assistance allowance (LASS), long-term institutional care for people with disabilities has been up to political debate and has also been described as a possible solution in some municipalities, in their planning of support and services to persons with disabilities. It is a worrisome development, which has been noticed mainly by the disability movement.

Another trend is the increasing focus on digitization in welfare, where municipalities are developing digital welfare services such as e-health and welfare technology. Digital technology is intended to replace some of the support and services that are currently provided to people with disabilities. The disability movement and many professionals in the field are critical of some of the digital services from an accessibility perspective, while other digital services are likely to facilitate opportunities to live a life as others in the community.

A third trend is marketization, with associated privatization of support and service for people with disabilities. In 2009, the Act on Freedom of Choice system applicable to health care and social services was introduced. The law refers to a procedure whereby the individual has the right to choose the supplier to perform the service and with which a contracting authority has approved and signed a contract. Since the law was introduced, payments to private providers have increased, and constitute an even larger share of the total costs of municipalities and regions. Nevertheless, in the last three years, the rate of increase has stopped and in some areas of care and services, the proportion of private providers is declining. In 2019, the government decided that the Public Employment Service should be reformed, which means that large parts of the employment service should be outsourced to private providers, but the extent not decided yet, in the end of 2019.



CONDUCTED INTERVIEWS

Moa Wahlqvist, PhD, National knowledge center for deafblindness

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