

ENIL Personal Assistance Survey

Country/region: Sweden

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PART 1: KEY INFORMATION ABOUT PERSONAL ASSISTANCE

LEGISLATION/POLICY	
Is there legislation covering personal assistance (PA)?	Yes, there is a Swedish national legislation with personal assistance being an individual right for those eligible.
Is PA currently provided on a pilot basis?	No, PA is not currently provided on a pilot basis but started as pilot projects in 1987 with the national law having been adopted 1993 and coming into effect 1994.
What is the total number of registered PA users in the country?	2012 figures: 3 876 persons using PA through municipalities; 15 892 persons using PA through the Swedish National Board of Health.
Has this number increased, decreased or stagnated (eg due to waiting lists) in the last 5 years?	The number has increased but some people have lost assistance from the national government due to the new interpretation of the legislation and have had to turn to the municipality for support.
Does everyone, regardless of type of impairment, have access to PA?	No, not everyone regardless of the type of impairment has access to PA. There are three categories of disability making someone eligible for personal assistance: 1/ intellectual disability, autism or the likes 2/ Adults with intellectual impairment caused by brain damage 3/ other major and permanent physical or mental impairments not due to normal ageing causing considerable difficulties in daily life Those excluded are those impairments not covered in the three categories, such as those persons with hearing and/or seeing impairments and those with deaf/blindness.

Does everyone, regardless of age, have access to PA?	<p>No not everyone regardless of age has access to PA.</p> <p>The age requirement is from 0 to 65: a person over 65 has a right to personal assistance only if the assistance was acquired before the age of 65.</p>
Are there restrictions on what PA can be used for?	<p>Yes there can be restrictions on what a PA can be used for and this will depend on where someone lives. Gardening is not permitted on the island of Gotland. One may receive assistance to get in and out of a car but not during the car journey if there is not an active need of the assistance. Shovelling of snow can be restricted.</p>
CHANGES IN LEGISLATION/POLICY	
Have there been any changes in legislation/policy restricting the use of PA in the last 5 years?	<p>Yes, there are new interpretations to the law which have someone for example being able to put a fork to mouth but not able to cut meat not receiving assistance to eat.</p>
Have any other limitations been introduced that prevent/restrict PA use in the last 5 years?	<p>Yes, the new interpretation of the law counts minutes for needed assistance and makes it harder for a person to be eligible for assistance from the national government. More emphasis is being put on family responsibility. Access to assistance at municipality level will depend on the financial situation of the municipality and the stamina of a person to appeal a case.</p>
If negative changes/restrictions have taken place in the last 5 years, what were the reasons (eg structural, financial etc.)?	<p>Changes in the interpretation of the Swedish legislation are due to financial reasons.</p>
ELIGIBILITY ASSESSMENTS	
Who carries out eligibility assessments for PA?	<p>City or State Board of Health social workers carry out assessments. Doctor certificates and certificates from physiotherapists are required.</p>
How often are assessments repeated?	<p>Assessments are repeated every two years when one has assistance from the national government, every year when having assistance through the municipality unless an exception has been made and they are carried out every two years.</p>
Is there a specific assessment	<p>There is a battery of questions used for assessment. See</p>

tool that is used?	http://assistanskoll.se/up/Bedomningsinstrumentet_3.pdf
FUNDING	
How are PA services funded?	<p>The Swedish state funds assistance partially when someone has been granted assistance from the state. To be eligible for state coverage a person must have basic needs amounting to 20 hours per week. The municipality is always responsible for the coverage of these first 20 hours per week of needed assistance. The national government then covers the hours above the first 20 hours per week of needed assistance.</p> <p>If the person does not have 20 hours of basic assistance needs and is granted assistance through the city, the city covers all the assistance granted.</p>
Is PA a means tested service?	No, PA is not means tested in Sweden.
What is the maximum number of PA hours per day/week that can be approved?	No, there is not a limit to PA hours per day – people can have 24/7 and someone may need two assistants per hour and would have more than 24/7.
What is the hourly rate that is funded?	284 SEK per hour (2015) is the amount paid by the national government to cover salary and other costs for assistance. This amount is also paid by most municipalities.
Are direct payments/personal budgets available for funding PA?	Yes, one can receive the money per hour of assistance to one's own bank account and administer the assistance through one's own company. Many people do the administration of their assistance through cooperatives like STIL, GIL or JAG all CILs. Then there are companies providing the service or even the municipalities.
What is the total number of direct payments/personal budget holders in the country?	The 19 768 receiving assistance could be direct holders but most choose not to be.
Are family members allowed to be paid as PAs?	Yes, family members are allowed to be personal assistants but there are some restrictions – if trips occur for pleasure the family member has to pay tax on the trip. Family members assistance provision cannot be administered through an individual company.
PROVIDERS AND SUPPORT	
Is there a choice of providers of PA services?	Yes, there is a choice in service provision with the choices being – own company, municipality, cooperative or companies providing the service.

If PA can be provided by user-cooperatives, do they have to be accredited?	Yes, all companies have to be accredited and the cooperatives as well.
Are PA users provided with training on how to manage their assistance?	Training is provided but depends on the provider. CILs will give training but companies and municipalities may not, Training in the CILs can be provided by other persons dependent on assistance but may also be provided by experts.
Are people with intellectual disabilities allowed to manage their own assistance?	Yes, people with intellectual disabilities are allowed to manage their own assistance and will receive support when needed. A service guarantor is used by the organisation JAG. STIL and GIL call the person providing support to a person in need as the vice work leader.
Are support services such as peer support/peer counselling/IL training provided by user organisations funded by the state or the local authority?	Peer support may be provided by CILs and may be provided through some companies. Peer counselling can be funded by the counties covered through the same legislation that covers personal assistance.

PART 2: ADDITIONAL INFORMATION

Please provide background information about the introduction of PA into legislation/policy (which actors were involved in advocating for PA, was there inspiration drawn from a certain country, which public stakeholders were needed to set it up, which challenges arose in the process of developing the legislation/policy, what resources were needed)?	During the latter part of the 1980s STIL – the Stockholm cooperative for personal assistance was able to obtain funding for a pilot project to test direct payments for about 20 users of personal assistance. The pilot project was copied by GIL – the Gothenburg cooperative. Both projects were successful and influenced the Swedish reform of 1994 through which the legislation LSS and LASS were adopted. These were legislations covering among other individual rights personal assistance. It was a right government who supported the reform with Bengt Westerberg as the social minister. The legislation passed in spite the financial crisis at the time. Inspiration came from the IL movement in the USA.
Are there any current challenges in implementing the PA legislation/policy?	The Swedish challenge is the new interpretation of the law covering PA services that is going against the implementation of the UN CRPD. Sweden received in the UN state review critic from the committee of the UN CRPD on the provision of PA services.
Has the legislation/policy on PA	CILs have been started to provide personal assistance and have

<p>led to empowerment of disabled people, setting up of CILs or cooperatives etc.?</p>	<p>contributed to the empowerment of people. As the legislation allows for choice there is an empowerment perspective baked into the legislation and the service provision.</p>
<p>Is PA used in the process of de-institutionalisation (to help people leave institutional care)?</p>	<p>Yes, PA was used in the Swedish DI process. The law was adopted in order to aid in the process of closure of institutions taking place in the 90s. By January 2000 all persons were to be moved from institutions.</p>
<p>Was any research carried out in the country on the costs of PA? If yes, please provide links or attachments.</p>	<p>The Swedish National Board of Health and Welfare produced the following study showing an increase in costs of assistance over the years as people ask for more hours than once was estimated. http://www.socialstyrelsen.se/Lists/Artikelkatalog/Attachments/9288/2007-131-33_200713134.pdf</p>
<p>If family members are allowed to work as PAs, is this considered problematic or beneficial?</p>	<p>This is up to the individual. Those persons using family members choose to do so and find it beneficial in doing. They may be able to avoid having someone strange to the family coming into the house at night. Some of those who do not choose family members, do so as they feel that family members may put their own interests first and then limit the independence of the individual in need of assistance.</p>