



## Independent Living under Threat in Europe: Sweden

The right to personal assistance<sup>1</sup> within Europe is under threat. This hinders disabled people from living independently, imprisoning them in their homes, and robbing those who previously used personal assistance of many of their rights<sup>2</sup>. The financial crisis and/or the economic downturn have been used as excuses to make changes in the vision countries have for disabled people, and how they provide the service of personal assistance. This article focuses on Sweden and highlights situations that are of concern to the Independent Living Movement and to ENIL – the European Network on Independent Living<sup>3</sup>. It is the first in a series of articles raising awareness about the deteriorating situation of personal assistance users in different countries and regions across the European Union (EU), such as the region of Wallonia in Belgium and the United Kingdom. All these countries have ratified the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD) and should not take any regressive measures that will affect the rights of disabled people<sup>4</sup>.

### Sweden Imposes Limits on the Right to Personal Assistance

*The Swedish law - LSS<sup>5</sup> - guaranteeing personal assistance for certain disabled people as a human right, has narrowed in interpretation<sup>6</sup>. This means that new applicants face a greater threat of not being granted personal assistance<sup>7</sup> and those who have had assistance for 20 years or so face losing their personal assistance partially or in full<sup>8</sup>.*

#### **National inquiries on personal assistance**

Since the adoption of the legislation in 1994, national enquiries have continuously been carried out, questioning the right to personal assistance. As the number of

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<sup>1</sup> ENIL defines Personal Assistance as a tool, which allows for independent living. Personal assistance is purchased through earmarked cash allocations for disabled people, the purpose of which is to pay for any assistance needed. Personal assistance should be provided on the basis of an individual needs assessment and depending on the life situation of each individual. The rates allocated for personal assistance to disabled people need to be in line with the current salary rates in each country. As disabled people, we must have the right to recruit, train and manage our assistants with adequate support if we choose, and we should be the ones that choose the employment model, which is most suitable for our needs. Personal assistance allocations must cover the salaries of personal assistants and other performance costs, such as all contributions due by the employer, administration costs and peer support for the person who needs assistance. See: <http://enil.eu/independent-living/definitions/>

<sup>2</sup> [https://www.stil.se/sites/default/files/innan\\_levde\\_jag\\_upplaga\\_2.pdf](https://www.stil.se/sites/default/files/innan_levde_jag_upplaga_2.pdf)

<sup>3</sup> The European Network on Independent Living (ENIL) is a Europe-wide network of disabled people, with members throughout Europe. ENIL is a forum for all disabled people, Independent Living organisations and their non-disabled allies on the issues of Independent Living. ENIL represents the disability movement for human rights and social inclusion based on solidarity, peer support, deinstitutionalisation, democracy, self-representation, cross disability and self-determination. See: [www.enil.eu](http://www.enil.eu)

<sup>4</sup> <http://www.mdpi.com/2075-471X/5/2/23>

<sup>5</sup> LSS – Lag om Stöd och Service till vissa funktionshindrade - 1993: 387 - [http://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/lag-1993387-om-stod-och-service-till-vissa\\_sfs-1993-387](http://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/lag-1993387-om-stod-och-service-till-vissa_sfs-1993-387)

<sup>6</sup> Social Insurance Agency. Decisions Overview—Personal Assistance [Rättsfallsöversikt—Personlig Assistans]. Stockholm: Social Insurance Agency, 2011. [https://www.forsakringskassan.se/wps/wcm/connect/33f1a187-53ea-4da5-aa0c-793e201257d8/anser\\_2011\\_1.pdf?MOD=AJPERES](https://www.forsakringskassan.se/wps/wcm/connect/33f1a187-53ea-4da5-aa0c-793e201257d8/anser_2011_1.pdf?MOD=AJPERES)

<sup>7</sup> Social Insurance Agency. Decisions Overview—Personal Assistance [Rättsfallsöversikt—Personlig Assistans]. Stockholm: Social Insurance Agency, 2011. [https://www.forsakringskassan.se/wps/wcm/connect/33f1a187-53ea-4da5-aa0c-793e201257d8/anser\\_2011\\_1.pdf?MOD=AJPERES](https://www.forsakringskassan.se/wps/wcm/connect/33f1a187-53ea-4da5-aa0c-793e201257d8/anser_2011_1.pdf?MOD=AJPERES)

<sup>8</sup> [https://www.stil.se/sites/default/files/innan\\_levde\\_jag\\_upplaga\\_2.pdf](https://www.stil.se/sites/default/files/innan_levde_jag_upplaga_2.pdf)

beneficiaries and the number of hours per beneficiary increased, decisions have been taken, leading to cuts in the service - in violation of the UN CRPD<sup>9</sup>. In 2016, the latest investigation of LSS was launched under the title "Review of activities under LSS and assistance allowance". The stated objective was to reduce the costs that the State pays for the assistance allowance. It was also stated that if any of the other LSS-services were to be further improved, any additional costs must be funded by reductions in the assistance allowance. The investigation is ongoing until October 2018. The explanatory documents for this enquiry (called "directives" in Swedish) explicitly state that there is a further need for cutting assistance benefits, in order to make savings for the State<sup>10</sup>.

### ***Reduction in the number of persons receiving assistance***

It is clear from the 2017 Swedish Insurance Report that the number of people receiving LSS from the Swedish government started decreasing in 2016, after redefining the right in recent years and as a result of decisions in numerous court cases. In December 2016, there were 15 691 people with the assistance allowance from the Social Insurance Agency, a decrease of 488 persons compared to the highest number in October 2015<sup>11</sup>. Those losing assistance from the national government can turn to their local municipality for the service of personal assistance. To qualify for personal assistance with funding from the national government, a person must have needs - including what is referred to as basic needs – with the basic needs being at least 20 hours per week. Basic needs in this case are classified in five groups: personal hygiene, dressing, eating, communicating and other needs, which require the assistant to have intimate knowledge of the person concerned. Even if a person does not come up to 20 hours of basic needs, he/she can still qualify for personal assistance from the municipality.

### ***Reduction in the hourly rate***

State funding for the hourly rate paid for the service<sup>12</sup> has decreased, as well as what the municipalities have to pay for<sup>13</sup>. The hourly rate paid for personal assistance is set each year by the government and is being revised; thus, the flat rate given by the government for personal assistance was raised only by 1.4% in 2015, despite the fact that this was lower than the assistants' agreed wage rise. The reasoning was that the flat rate has been increased too much in the previous years. The low increase of 1.4%<sup>14</sup> continued in 2016, and in 2017 it fell to only 1.05%<sup>15</sup>. ENIL finds this development a danger to personal assistance as a real profession. Meanwhile,

<sup>9</sup> <http://www.mdpi.com/2075-471X/5/2/23>

<sup>10</sup> Latest enquiry Dir: 2016:40

<http://www.regeringen.se/49bde0/contentassets/72147037df874b5da65fb16afd376244/oversyn-av-insatser-enligt-lss-och-assistansersattningen.pdf> - Med hänsyn till kraftiga kostnadsökningar inom assistansersättningen behöver även ytterligare besparingar göras. (With consideration to the substantial cost increases for personal assistance, there is a need for further saving.)

<sup>11</sup> <https://www.forsakringskassan.se/wps/wcm/connect/d603e099-7176-4471-898f-33c55a4ccd39/socialforsakringsrapport-2017-04.pdf?MOD=AJPERES&CVID=>

<sup>12</sup> <http://www.regeringen.se/contentassets/e926a751d9eb4c978c4d892c659ebc8e/utgiftsomrade-9-halsovard-sjukvard-och-social-omsorg> and <https://assistanskoll.se/up/F--rslag-till-timbelopp-ASE-f--r-2015-.doc>

<sup>13</sup> <https://assistanskoll.se/20161230-HFD-dom-ger-kommuner-rett-setta-legre-timbelopp.html>

<sup>14</sup> <https://assistanskoll.se/up/F--rslag-till-timbelopp-ASE-f--r-2015-.doc>

<sup>15</sup> <http://www.regeringen.se/contentassets/e926a751d9eb4c978c4d892c659ebc8e/utgiftsomrade-9-halsovard-sjukvard-och-social-omsorg>

more and more municipalities have paid an hourly amount for personal assistance that is lower than what they are paying for the assistance provided by the municipality directly. They believe that they only need to pay for the so-called actual costs, and this was confirmed in a judgment of the Supreme Administrative Court Case No. 753-756-16 in December 2016<sup>16</sup>.

### ***Hostile rhetoric towards assistance users***

With the process of reviewing and limiting access to the services, the rhetoric in the national debate has become more harsh, and was described as hateful by Desirée Pethrus, the politician heading the most recent enquiry<sup>17</sup>. A debate that focused on criminal abuse of payments within personal assistance led to an enquiry on the issue in 2012<sup>18</sup> and in 2015, the Swedish Finance Minister released a controversial statement saying Sweden needs to save on personal assistance, among other areas, in order to finance the increased number of migrants<sup>19</sup>. This statement showed how the right to support – which many disabled people need - could easily disappear when politicians start prioritising the rights of one group over another.

### ***Redefining basic needs***

The Social Insurance Agency redefined basic needs in November 2007, meaning that only 'integrity of the close parts of the bodies' became the basis for basic needs for dressing and personal hygiene. This has meant that, for example, washing of the hair is not a basic need, nor is putting on outer clothing<sup>20</sup>. Judgments from the Swedish Supreme Administrative Court on, for example, eating as a basic need, have also restricted the right to personal assistance<sup>21</sup>. After the court decision, if the person her/himself can bring the food to their mouth and eat it, it is considered that there is no basic need of assistance at mealtimes, as there is no integrity offence. It is therefore irrelevant if the person cannot cut meat or other food items, in order to put them on the fork or to put them in their mouth, as this does not affect the integrity of the person. In such cases, it is considered that anyone can carry out this task, for example, someone from the home-help services.

Both the regular guidelines and court cases have changed the determining factors for the 20-hour requirement of basic needs per week, needed in order to qualify for assistance from the Swedish Social Insurance Agency. The assessment and granting of assistance is now based on minutes<sup>22</sup> of needs and the original intentions of the law are being lost. People are losing their jobs, as a result of losing their personal assistance, in violation of the right to employment, as guaranteed by the UN CRPD<sup>23</sup>.

The development has been criticized by Thomas Hammarberg, former

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<sup>16</sup> <http://www.hogstaforvaltningsdomstolen.se/Domstolar/regeringsratten/Avgöranden/2016/December/753--756-16.pdf>

<sup>17</sup> <http://assistanskoll.se/20170213-Desiree-Pethrus-syvende-sist-politike-beslutar-kostnadsutvecklingen.html>

<sup>18</sup> fusk debatten - <http://www.regeringen.se/rattsdokument/statens-offentliga-utredningar/2012/02/sou-20126/>

<sup>19</sup> <https://assistanskoll.se/20151023-Finansministern-vill-spara-assistansersättning.html>

<sup>20</sup> Försäkringskassan. (2007). *Informationsmeddelande IM 2007:161*. Stockholm: Försäkringskassan.

<sup>21</sup> KRNS 564-08

<sup>22</sup> [https://assistanskoll.se/\\_up/Bedomningsinstrumentet\\_3.pdf](https://assistanskoll.se/_up/Bedomningsinstrumentet_3.pdf)

<sup>23</sup> [https://www.stil.se/sites/default/files/innan\\_levde\\_jag\\_upplaga\\_2.pdf](https://www.stil.se/sites/default/files/innan_levde_jag_upplaga_2.pdf)

Commissioner for Human Rights at the Council of Europe (2006 – 2012). He noted that Sweden is violating the UN CRPD, when the previously established rights are being limited<sup>24</sup>.

**An overview of the changes that have occurred in the implementation of the LSS legislation follows below:**

- Support for the basic need dressing no longer includes outerwear. Support for the basic need meals is only given if the person her/himself cannot bring the food to their mouth. This was established by the Supreme Administrative Court judgment in Case No. 5321-07 17 (June 2009)<sup>25</sup>.
- In June 2015, the Supreme Administrative Court judgment in Case No. 3527-14, HFD 2015 ref. 46, established that the fifth basic need - "other assistance that requires detailed knowledge" - should only be granted when a person has psychosocial disabilities. This has changed the assessment of granted hours for the so-called active supervision<sup>26</sup>.
- The Supreme Administrative Court judgment in Case No. 1-12 -HFD 2012 Ref 41 (July 5<sup>th</sup>, 2012) led to self-care no longer being counted as a basic need<sup>27</sup>. This was implemented in May 2016, when the Social Insurance Agency introduced a new form for medical reporting. This means, for instance, that the time needed for gavage feeding (i.e. tube feeding) is no longer recognized as a basic need. The verdict of the Administrative Court of Appeal in Gothenburg, case no. 3208-16, 2016-12-20 found gavage feeding qualifying as a basic need. The court stated that it is to be considered as self-care. The court continued by stating that gavage feeding falls under the basic need of meals. As the self-care is linked to meals, gavage feeding can be covered as a basic need. The decisive element is the private and intimate character of the help required in connection with the gavage feeding. The Swedish Insurance Agency appealed this verdict to the Supreme Administrative Court.

***Retroactive payment of allowance***

- Until October 2016, assistance allowance was paid in advance on the 20<sup>th</sup> of the same month that the assistance is performed. From October 1, 2016 the Social Insurance Agency pays out the funding for assistance retroactively, based on the reporting of delivered assistance. This means that the payment is not earlier than 20 days after. This applies to all assistance providers, except the so-called "own employers" (i.e. people who hire their own assistants)<sup>28</sup>.

***Needs assessment tools in minutes***

- In a parallel development, it has become a practice to count the amount of time needed for basic needs in minutes during the assessment. Time for going to the

<sup>24</sup> <https://assistanskoll.se/20131022-Hammarberg-ratificerat-FN-konventionen-inte-begrnsa.html>

<sup>25</sup> <http://www.domstol.se/Domstolar/regeringsratten/Avgöranden/2009/Juni/5321-07.pdf>

<sup>26</sup> HFD 2015 ref. 46

<sup>27</sup> <http://www.hogstaforvaltningsdomstolen.se/Domstolar/regeringsratten/Avgöranden/2012/Juli/1-12.pdf>

<sup>28</sup> <https://assistanskoll.se/up/Efterskottsbetalning-assistans-slutversion.pdf>

toilet or showering is measured in active minutes. A needs assessment instrument was introduced in 2012, with the number of minutes specified and assessed as reasonable for the activity, as opposed to what the social worker would estimate<sup>29</sup>. All basic and other personal needs, everything from going to the bathroom, transport, or to going to church, is counted in active minutes.

### ***Repaying unspent funding***

- The so-called “own employers”, who hire their own assistants, cannot keep funding that has not been spent, as per legislation which came into effect on July 1, 2008. Leftover assistance funding must now be paid back to the insurance agency within a six-month settlement period. “Own employers” therewith lose the ability to save money for unforeseen expenses<sup>30</sup>.

### ***More controls in the new legislation***

- Since July 1, 2013, providers are obliged to report on the user in case s/he provides false information. Assistance is not paid if labour laws are not followed, if the assistant is under age or does not have a permit to work in the EU. Inspectorate for Health Care can exercise control through home visits when family members are assistants<sup>31</sup>.

### ***Licensing obligation to organize personal assistance***

- From June 1, 2011, anyone who wants to start as an assistance provider needs to get permission from the Health and Social Care Inspectorate (IVO). Assistance providers need to meet certain licensing requirements and self-employed providers need to register with the National Board<sup>32</sup> and with IVO.

## **Conclusion**

The Government is able to propose draft legislation if they feel that the administrative court judgments are having a negative effect on disabled people, but this has not happened. Instead, there has been consistent introduction of new investigations or reports from various authorities, where the effects of changes brought on by new court cases were implemented and used to limit access to personal assistance.

The development of hostile rhetoric towards disabled people, from exaggerated reports concerning criminal abuse of payments within personal assistance<sup>33</sup>, to suggestions for resources to be taken from disabled people to fund migrants (as stated by the minister of finance Magdalena Andersson), is very worrying. The rhetoric has contributed to a more hostile society, cuts and a view that disabled people are cheating the system. This contributes to disabled people losing their freedom and a good quality of life.

Personal assistance costs money, but this spending should be seen in a wider

<sup>29</sup> [https://assistanskoll.se/\\_up/Bedomningsinstrumentet\\_3.pdf](https://assistanskoll.se/_up/Bedomningsinstrumentet_3.pdf)

<sup>30</sup> <http://www.regeringen.se/rattsdokument/proposition/2008/02/prop.-20070861/>

<sup>31</sup> [https://assistanskoll.se/\\_up/budgetproposition-assistans-2012.pdf](https://assistanskoll.se/_up/budgetproposition-assistans-2012.pdf)

<sup>32</sup> <https://data.riksdagen.se/fil/44FC3D50-D4C3-4124-8223-3B7AFFE69EE6>

<sup>33</sup> <https://www.stil.se/sv>



perspective, rather than as just something that must be cut.

- It is a cost that compensates for other costs, such as healthcare, unemployment, training of workers and institutionalisation;
- It facilitates access to full participation and a good quality of life for disabled people;
- It is a measure against unemployment of both those who are disabled, but also of those who work as personal assistants;
- It allows family members to work, rather than stay at home and care for their disabled relative;
- It is a measure to reduce poor health among disabled people; and there are other arguments.

There is a tendency to forget that personal assistance allows people to take part in society, which allows them to access their human rights: through employment, education, family life and politically. Personal assistance is also cheaper per hour than the cost of home help, which does not contribute to full participation in society.

With the court cases and changes in the interpretation of LSS, there is now a need to review current legislation. Not with the goal of reducing access to personal assistance and saving money, but in order to regain the original intentions of the law, allowing disabled people to live integrated in society and for Sweden to stand proud in its solidarity with all citizens.

**ENIL, together with allies, call on the European Commission and the European Parliament to ensure that all Member States, including Sweden, comply with the UN CRPD and that they review all measures and actions that are limiting access and availability of personal assistance.**

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