



## European Network on Independent Living

# Personal Assistance Services in Europe 2015

### Introduction

The European Network on Independent Living (ENIL) is a non-governmental organization working in the disability field. ENIL promotes and supports the Independent Living Movement in Europe since 1989. The core element of ENIL is promoting Independent Living (IL), self-determination and human and civil rights, through Independent Living and anti-discrimination legislation and empowerment of disabled people. It advocates and lobbies for Independent Living by promoting the values, principles and practices to enable full citizenship of disabled people. The goal is to improve full participation of people with disabilities in society and to increase involvement of disabled people within the Independent Living Movement throughout Europe.

One of the pillars of the Independent Living Movement is personal assistance (PA), which ENIL defines as a tool allowing for Independent Living<sup>1</sup>. PA should be provided on the basis of an individual needs assessment and depending on the life situation of each individual. The funding allocated for personal assistance to disabled people need to be in line with the current salary rates in each country. According to the IL philosophy all disabled people must have the right to recruit, train and manage their assistants with adequate support, and the disabled person should be the one that choose the employment model which is most suitable for their needs. PA allocations must cover the salaries of personal assistants and other performance costs, such as all contributions due by the employer, administration costs, personal assistant training and peer support for the person who needs assistance.

PA provides an opportunity for empowerment and inclusion of disabled people. It is considered a human right by both the Independent Living movement and the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD). However, despite the fact that PA is supported by Article 19 of the CRPD, which most European countries have signed and ratified, many still do not have PA legislation. Some countries have passed PA legislation that does not reflect the philosophy of the IL Movement or the CRPD. This allows for the breaching of human rights. It also confirms the belief of ENIL that politicians



are lacking in knowledge about legislation and on the real situation of disabled people. This lack of political will directly affect thousands of lives on a daily basis. ENIL decided in 2011 to research the availability of PA services within countries of the Council of Europe area collecting information to compare country situations on PA legislation. Research was carried out by ENIL between 2011 and 2013 including a desktop research and the dissemination of a survey. Disability experts from 21 European countries were involved in that process. Information was presented in a comprehensive way in tables format (one for each country). These PA tables, together with a summary report can be found here: <http://www.enil.eu/policy/personal-assistance-tables/>

In 2015 ENIL has updated the collected data contacting again disability experts with answers from the following 20 countries: Belarus, Belgium, Bulgaria, Cyprus, Denmark, Estonia, France, Georgia, Greece, Italy, Latvia, Macedonia, Netherlands, Norway, San Marino, Slovenia, Spain, Switzerland, Sweden, UK. Compared to 2013, four new countries were added – Estonia, Georgia, Macedonia and Switzerland. Unfortunately, ENIL could not collect information from Germany, Iceland, Ireland, Serbia and Slovakia, which all participated in ENIL's previous research project.



Research questions were divided in two parts covering the following areas:

- Part 1: Key information about personal assistance
  - Legislation/policy
  - Changes in legislation/policy
  - Eligibility assessments
  - Funding
  - Providers and support
  
- Part 2: Additional information
  - Background information about the introduction of personal assistance into legislation/policy
  - Current challenges in implementing the personal assistance legislation/policy
  - Personal assistance and empowerment
  - Personal assistance role in the process of de-institutionalisation
  - Research on costs of personal assistance
  - Family members as personal assistants

All research questions can be found in Appendix 1.



## Main findings from Part 1:

### **LEGISLATION/POLICY**

- **Legislation covering personal assistance (PA)**

Twenty countries have completed the PA Table template prepared by ENIL. Since 2013 four new countries were added to the data collection – Estonia, Georgia, Macedonia and Switzerland. Countries included in the 2013 report but missing from this update are Germany, Iceland, Ireland and Slovakia. Thirteen countries out of the twenty have available PA services including: Belgium, Denmark, Estonia, France, Italy, Latvia, Netherlands, Norway, Slovenia, Spain, Switzerland, Sweden and UK. PA service is also available in Bulgaria, however, it is not grounded in national law, and therefore does not fit ENIL's definition of personal assistance. The Bulgarian data covers only a program which some disabled people in the capital of Sofia benefit from. Similarly, in Slovenia there is no national law regulating PA services, instead different NGOs provide such service, each with different rules and criteria, thus creating chaos in the system. These services are projects through an unemployment measure.

- **PA provided on a pilot basis**

The provision of PA on a pilot basis could be the first step towards the introduction of a national program. At present PA service is provided on a pilot basis only in Slovenia. However, this situation has been ridiculously prolonged since 1996. There is a number of disabled people's organizations (DPOs) providing PA with funding from different sources, but there is no national program. Therefore, not all disabled people have access to PA in accordance with their actual needs.

- **Number of registered PA users**

In 9 of the countries (Belarus, Bulgaria, Cyprus, Georgia, Greece, Macedonia, Netherlands and San Marino) no data for the number of PA users is available. From these only the Netherlands provides PA service. This lack of data is disturbing as it does not allow neither governments, nor NGOs to make reliable estimation of the costs when a pilot program is created.



Since 2013 the number of PA users in some European countries has increased. For example in Latvia, Spain, Sweden, significantly in the UK (100,000 across Scotland and Wales in 2013 and 250,000 in 2015<sup>2</sup>) and slightly in Norway (3040 in 2013 and 3600 in 2015).

- **Increase/decrease or stagnation of the registered PA users**

Of the countries where information on the number of PA users is available, 9 report increase (Wallonia/Belgium, Italy, Latvia, Netherlands, Norway, Spain, Sweden, Switzerland and the UK) and 3 (Bulgaria, Macedonia and Georgia) report stagnation. The main reasons for the stagnation are considered to be budget cuts and waiting lists.

- **Type of impairment having impact on the access to PA service**

In general, there are no impairment-based restrictions for access to PA service. However, in practice people with psycho-social disabilities or cognitive impairments in some countries (Bulgaria, Italy, Slovenia, Spain, Switzerland, Sweden and the UK) receive very limited support and thus become victims of discrimination. A potential reason for this stigmatization is the lack of understanding of the needs which are not directly visible. However, this is not an excuse and is unacceptable when speaking about equal, human rights.

In Netherlands only people with a personal care budget may decide to use it to hire a PA. The provision of such budgets is not dependent on the type of impairment. However, providers may judge a person's ability to manage a budget, which limits the access to the PA service.

- **Age affecting the access to PA service**

UK, Latvia, Norway and Netherlands are the only countries whose PA legislation is not age-bounded – everybody, regardless of age, has the same right to receive PA support. In Bulgaria (only referring to the PA program in Sofia) there are no official age restrictions, but privilege is given to younger persons. In France and Denmark people above 65 years of age also receive limited support. In Slovenia, Sweden and Switzerland the age limit of 65 years is explicitly specified. The legislation in this area in Europe has not changed since 2013.



- **Restrictions on what the PA can be used for**

In most countries with PA legislation there are restrictions in what an assistant is allowed to do. For example, in Denmark and Sweden gardening, shovelling and snow cleaning cannot be part of PA's duties. In France, Netherlands and Spain social and leisure activities are generally ignored (e.g. only 1 hour allocated). Health-related activities are forbidden in France, Norway and Flanders. The three countries which do not impose restrictions on the PA service are Bulgaria, Belgium (but only Wallonia) and Switzerland. However, for instance in Bulgaria, the hours allowed for personal assistance are often so limited that in practice the disabled person prefers to use them for urgent needs and thus social activities remain ignored.

## **CHANGES IN LEGISLATION/POLICY**

- **Changes in legislation/policy restricting the use of PA services**

PA legislation is dynamically changing – only one of the 10 countries with such legislation reported that there were no changes in the last 5 years. In 7 of the countries the changes have been towards deterioration. A dramatic change is experienced by the PA users in the UK with the closure of the centrally funded Independent Living Fund (ILF), which has provided financial support for PA to disabled people across UK <sup>3, 4, 5, 6</sup>. All ILF users' funds in England (estimated 17,500) were transferred to local authorities. From early Freedom of Information requests it appears that funds will be cut for many ex-ILF users and in some cases night time support will be removed. All this will have negative impact on the PA use and on the lives of disabled people. Scotland and Northern Ireland will retain a central fund through the newly created ILF Scotland. Wales will have cash transferred to local authorities.

The only country, which reports positive changes in legislation, is Spain, where PA budgets have been increased and more types of disabilities are now considered eligible for support. However, the government is currently considering the introduction of a compulsory two-year training for personal assistants – a measure that is considered by experts in the disability and human rights area not only to be unnecessary, but to overcomplicate the system and make it even more clumsy.



- **Limitations that prevent/restrict PA use**

Further restrictions of the use of PA service have been introduced in several countries. In Sweden a new interpretation of the law has led to many disabled people being considered ineligible to use the centrally funded PA service. In addition, more emphasis is being put on family responsibility. Access to assistance at municipality level now depends on the financial situation of the municipality and the stamina of a person to appeal a case. In the UK the situation is not more optimistic – the money available for care has reduced, resulting in tighter eligibility for services. This means that many disabled people are no longer eligible for support. The quality of the service has also decreased as more and more often visits from agency workers last no more than 15 minutes which is apparently insufficient time for proper work. In Italy there have been cuts on public spending and the number of people on waiting lists has also increased. Furthermore, the newly introduced co-participation in funding has also its negative implications on the service provided.

- **Reasons for introducing negative changes/restrictions**

In 7 of the countries with PA legislation (UK, Sweden, Italy, Spain, France, Denmark and Belgium's Wallonia) the reasons for the changes in PA service are financial. This is not surprising considering the overall economic situation in Europe in the last years. Only Switzerland reports (although only as speculation) that the reason might be related to poor management instead of finances – the responsible agencies might have hired too many staff members, expecting a much larger demand than actually occurred.

## **ELIGIBILITY ASSESSMENTS**

- **Who carries out eligibility assessments for PA?**

In most countries with PA legislation (Belgium, Bulgaria, France, Italy, Norway, Spain and the UK) assessment happens at the local level and is usually carried out by social workers. In Spain there is no separate PA assessment. A general assessment is carried out of person's eligibility to use the different services and budgets, one of which is the PA budget.



- **How often assessments are repeated?**

Most countries do re-assessment on a yearly basis. This is the case in Belgium (only Wallonia), Bulgaria, Denmark, Latvia, Norway and the UK. In other countries the time frame varies according to the specific type of impairment or the service provider. For example in Sweden reassessment happens every two years if the provider is at the national government and every year if assistance is provided by the municipality. In Slovenia the reassessment is not fixed, it depends on the NGO that provides the support. In Spain and Flanders in Belgium there is no requirement for reassessment.

- **Tools for assessment**

Different specialised tools are used in the different countries. Usually, these are in the form of questionnaires aiming to determine the type of support needed and its frequency.

## **FUNDING**

- **Funding of PA services**

Funding of PA service in most countries happens at both levels – national and local/regional. This is the case with Denmark, France, Italy, Latvia, Netherlands, Norway, Slovenia, Sweden, Spain and the UK. There are also countries where insurance companies take this responsibility – e.g. in Norway and Switzerland.

- **Means tested access**

PA is a means tested service in Flanders (Belgium), France, Italy, the Netherlands, Norway, Spain and the UK and some users may have to contribute to the cost of having a PA. In Bulgaria, Wallonia (Belgium), Latvia, Denmark, Sweden and Switzerland it is fully funded by either local or national authorities.



- **Maximum number of PA hours per day/week**

As can be expected these numbers vary dramatically in the different countries. There are countries where users can have 24 hours of PA per day or even more in cases where a person needs two assistants per hour. However, these are exceptions – Denmark, France, Sweden and the UK. In most countries there are restrictions of the number of hours.

- **Hourly rate funded**

It is difficult to make comparison between the countries as the hourly rate is very much dependant on the overall cost of living. In some countries, for example Bulgaria, the amount is so low that PA users have immense difficulties in finding personal assistants outside their families.

- **Direct payments**

Direct payments is considered by many to be the most empowering, from the perspective of the users, way to manage PA service. However, not all countries with PA legislation have introduced direct payments. For example, disabled people in Bulgaria and Slovenia do not have a chance to opt for direct payments. In other countries, such as Italy and Belgium, there are differences between the regions. The Flanders region in Belgium has introduced direct payments, while Wallonia has not.

- **Family members as PAs**

This topic often provokes hot debates and so far no universal decision has been taken even at the territory of one country. The issue is highly culture specific and some trends for this can be seen from the survey results. For example countries like Spain and Bulgaria allow PAs to be family members and people there often use this opportunity. In countries like Sweden, the UK, Belgium (Wallonia region) and the Netherlands certain restrictions are implied. There are also countries which do not allow family members to provide PA support – e.g. Switzerland.



## **PROVIDERS AND SUPPORT**

- **Choice of providers of PA services**

In nine countries with PA legislation there is a choice of providers of PA services (Denmark, France, Italy, Latvia, Netherlands, Norway, Spain, Sweden and the UK). However, in some countries (e.g. Italy and Norway) there are differences between municipalities and the availability of a choice of providers depends on the particular municipality. In Switzerland and Bulgaria there is no option to choose between different providers – only self-employed people can be hired.

Of those countries which have user cooperatives, those that require accreditation are France, Italy, Netherlands, Norway and Sweden. The rest of the countries either do not have cooperatives, or accreditation is not a requirement.

- **Training of PA users**

Of the countries with PA legislation Denmark, Italy, Norway, Sweden and the UK provide some kind of training for the PA users on how to recruit and manage their assistance. This is either provided by experts (psychologists, social workers) or by other disabled persons. However, the latter exists in very few countries – like in Sweden for instance. This shows that peer support is still rarely available for disabled people to use. Good practice is evident in the UK where PA users train their assistants by themselves.

The general lack of training of assistants by the PA users themselves is a problem because according to the human rights perspective and the social model of disability it is disabled people who are experts on their own needs. No external 'expert' (no matter what kind of profession they possess) can know better than the persons themselves how another person can assist them. Moreover, the importance of such training is essential if a real professional bond will be established between the disabled person and the personal assistant.<sup>7</sup>



- **Are people with intellectual disabilities allowed to manage their own assistance?**

Eight countries report that people with intellectual disabilities are allowed to manage their PA themselves. These are Belgium, France, Netherlands, Norway, Spain, Sweden, Switzerland and the UK. However, in reality in most of these countries family members manage the PA support. In Bulgaria, Denmark and Italy people with psycho-social disabilities are deprived from their right to use PA.

## **Main findings from Part 2:**

- **Background information**

A driving force for change in most countries has been the Independent Living Movement. Either individuals or organisations of disabled people have initiated the process of development of PA service and legislation. This process first began in the countries from Western and Northern Europe – around the 1970s in Denmark, a few years later in France, in 1987 in Belgium with the foundation of Independent Living Flanders (an Independent Living organisation) and around the same time in Sweden and the UK. More recently legislation changes were introduced in Estonia, Latvia and Bulgaria.

- **Challenges**

The challenges that PA users throughout Europe meet nowadays have not changed much since 2013. Disabled people are still fighting to receive more hours of assistance, better salaries for their assistants and access to PA regardless of the type of their impairment. One of the main reasons for these challenges is financial, but not less important is the difficult transition from the medical to the social model of disability. Changing the mindset of society and decision makers is a challenge that needs to be tackled persistently.



- **Empowerment**

In general it is thought that the PA legislation has led to the empowerment of disabled people. In Belgium, Norway, the UK, Estonia and Sweden it has helped disabled people to live more independently. Having a personal assistant for many is a chance to leave home and not live with their parents as adults, to have more active and meaningful life. Many grassroots organisations of disabled people and cooperatives have been established after the official recognition of the right of personal assistance.

- **De-institutionalisation and PA**

PA can be used as a tool in the process of DI. People who live in institutions could benefit from that kind of service, which could help them leave the institution and start living independently. However, according to the data collected, in most countries PA is not used as a measure in the DI process. It contributes to the DI process, but marginally. Most PA users have never lived in an institution (reported by Belgium and Denmark). France reports that institutional care is still highly popular in the country. Similar comments come from Bulgaria where a re-institutionalisation process is witnessed. This means that people are moved from larger institutions to small group homes which cannot be considered to be community-based service.

- **Research on the costs of PA**

The research on the costs of PA is limited or there is no publicly available data from such research. Bulgaria, France, Italy and Latvia do not have information of any research of this kind to have taken place. The Netherlands, Norway and Switzerland report the existence of such data, but no further details are provided. Slovenia reports one research on the costs of PA, carried out for the ENIL survey Comparing the Cost of Independent Living and Residential Care in 2012. The Swedish National Board of Health and Welfare has produced a study showing an increase in costs of assistance over the years as people ask for more hours than once was estimated. Overall, it can be seen that governments still do not put enough efforts in research work.<sup>8</sup>



## Conclusions:

Several conclusions could be drawn from this summary of the updated data on the situation of personal assistance collected from 20 European countries. Most of them repeat the conclusions from the report published by ENIL in 2013. There is still a great variation in legislation and availability of PA services across Europe. A matter of great concern is that there are still countries where no PA service and legislation exist. There are still discriminatory provisions which go against the UN CRPD – especially restrictions of the access to PA service on the basis of age or type of disability. Another serious challenge are the financial cuts that have been introduced in many countries, disproportionately affecting disabled people.<sup>9</sup>

## Recommendations:

The fact that this report repeats the recommendations produced two years ago shows that there is a lack of political will the situation of disabled people to be improved. ENIL still emphasises the urgent need for the national governments to:

- **Enact legislation for PA services**, which is compliant with the CRPD and reflects the philosophy of the Independent Living Movement;
- Ensure that the **responsibility** for PA services is assumed **at the national level**, to ensure equal access throughout the country;
- Ensure that PA services are provided on the basis of **an individual needs assessment** and are dependent upon the life situation of each individual. This should be in line with a **social understanding of disability**, and not carried out using a medical approach;
- Ensure that the PA legislation and services **do not discriminate** based on type or perceived level of disability;
- Ensure that the rates allocated for personal assistance to disabled people are **in line with the current salary rates** in each country;
- Give disabled people the **right to recruit, train and manage** their own assistants, with adequate support, if preferred;
- Facilitate an **exchange of ideas and knowledge** about good legislation and practice in the area of personal assistance with other European countries;
- Improve the **collection of relevant data** to support advocacy and development of good legislation in this area.



## **Footnotes:**

<sup>1</sup> ENIL's key definitions on Independent Living <http://www.enil.eu/policy/>

<sup>2</sup> These are estimates supplied by Sue Bott via figures from Skills for Care

<sup>3</sup> Article on the ENIL website, published on 25/03/2013: *"The Fight for the Independent Living Fund in the UK: DPAC and Disabled People Take the Government to Court"*:

<http://www.enil.eu/news/the-fight-for-the-independent-living-fund-in-the-uk-dpac-and-disabled-people-take-the-government-to-court/>

<sup>4</sup> Article on the ENIL website, published on 07/11/2013: *"Victory-Appeal Court in London Quash Decision to Close the Independent Living Fund"*:

[www.enil.eu/news/victory-appeal-court-in-london-quash-decision-to-close-the-independent-living-fund/](http://www.enil.eu/news/victory-appeal-court-in-london-quash-decision-to-close-the-independent-living-fund/)

<sup>5</sup> Article on the ENIL website, published on 09/04/2015: *"UK Disabled People Appeal to the UN Over Independent Living Fund Closure"*:

<http://www.enil.eu/news/uk-disabled-people-appeal-to-the-un-over-independent-living-fund-closure/>

<sup>6</sup> Article on the ENIL website, published on 30/06/2015: *"Disabled People Against Cuts Storm the British Parliament Against Closure of the Independent Living Fund"*:

<http://www.enil.eu/news/disabled-people-against-cuts-storm-the-british-parliament-against-closure-of-the-independent-living-fund/>

<sup>7</sup> Training Manual "Peer Support for Independent Living"

[http://www.enil.eu/wp-content/uploads/2012/06/Peer-Support-Training-Manual-Final\\_281014.pdf](http://www.enil.eu/wp-content/uploads/2012/06/Peer-Support-Training-Manual-Final_281014.pdf)

<sup>8</sup> ENIL Survey "Comparing the Costs of Independent Living and Residential Care"

[http://www.enil.eu/wp-content/uploads/2012/06/Cost-survey\\_FINAL1.pdf](http://www.enil.eu/wp-content/uploads/2012/06/Cost-survey_FINAL1.pdf)

<sup>9</sup> Article on the ENIL website published on 05/05/2014: *"Stop Disability Cuts" Campaign Culminates In a Number of Awareness Raising Activities Throughout Europe to Mark the European Independent Living Day, 5<sup>th</sup> May 2014*

<http://www.enil.eu/news/stop-disability-cuts-campaign-culminates-in-a-number-of-awareness-raising-activities-throughout-europe-to-mark-european-independent-living-day-5th-may-2014/>



## Appendix 1

### ENIL Personal Assistance Survey

**Country/region:**

**Updated on: (date)**

**Contact Person:**

**ENIL Contact Person: (to be completed by ENIL)**

#### PART 1: KEY INFORMATION ABOUT PERSONAL ASSISTANCE

LEGISLATION/POLICY	
Is there legislation covering personal assistance (PA)?	YES/NO  If YES, please specify what type of legislation and at which level of government (national, regional, local):
Is PA currently provided on a pilot basis?	YES/NO  If YES, please specify the year when it started:
What is the total number of registered PA users in the country?	
Has this number increased, decreased or stagnated (eg due to waiting lists) in the last 5 years?	Increased Decreased Stagnated due to waiting lists



Does everyone, regardless of type of impairment, have access to PA?	YES/NO  If NO, which impairment groups are excluded:
Does everyone, regardless of age, have access to PA?	YES/NO  If NO, which age groups are excluded:
Are there restrictions on what PA can be used for?	YES/NO  If YES, please explain:
<b>CHANGES IN LEGISLATION/POLICY</b>	
Have there been any changes in legislation/policy restricting the use of PA in the last 5 years?	YES/NO  If yes, please explain:
Have any other limitations been introduced that prevent/restrict PA use in the last 5 years?	YES/NO  If yes, please explain?
If negative changes/restrictions have taken place in the last 5 years, what were the reasons (eg structural, financial etc.)?	
<b>ELIGIBILITY ASSESSMENTS</b>	
Who carries out eligibility assessments for PA?	
How often are assessments	



repeated?	
Is there a specific assessment tool that is used?	YES/NO  Please specify:
<b>FUNDING</b>	
How are PA services funded?	By the state: YES/NO By the regional or local authority: YES/NO Both: YES/NO  If by BOTH, please explain:
Is PA a means tested service?	YES/NO  Please specify if there are circumstances when individuals have to contribute to payment of the service:
What is the maximum number of PA hours per day/week that can be approved?	
What is the hourly rate that is funded?	
Are direct payments/personal budgets available for funding PA?	YES/NO
What is the total number of direct payments/personal budget holders in the country?	



Are family members allowed to be paid as PAs?	YES/NO
<b>PROVIDERS AND SUPPORT</b>	
Is there a choice of providers of PA services?	YES/NO  Please specify:
If PA can be provided by user-cooperatives, do they have to be accredited?	YES/NO
Are PA users provided with training on how to manage their assistance?	YES/NO  If YES, please specify who provides the training:
Are people with intellectual disabilities allowed to manage their own assistance?	YES/NO  Please specify if there needs to be a service guarantor or something similar:
Are support services such as peer support/peer counselling/IL training provided by user organisations funded by the state or the local authority?	YES/NO



## PART 2: ADDITIONAL INFORMATION (please complete if possible)

<p>Please provide <b>background information about the introduction of PA into legislation/policy</b> (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)?</p>	
<p>Are there any current <b>challenges</b> in implementing the PA legislation/policy?</p>	
<p>Has the legislation/policy on PA led to <b>empowerment</b> of disabled people, setting up of CILs or cooperatives etc.?</p>	
<p>Is PA used in the process of <b>de-institutionalisation</b> (to help people leave institutional care)?</p>	
<p>Was any research carried out in the country on the <b>costs</b> of PA? If yes, please provide links or attachments.</p>	
<p>If <b>family members</b> are allowed to work as PAs, is this considered problematic or beneficial?</p>	



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