

## ENIL Personal Assistance Survey

Country/region: *France*

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### PART 1: KEY INFORMATION ABOUT PERSONAL ASSISTANCE

LEGISLATION/POLICY	
Is there legislation covering personal assistance (PA)?	<p>YES</p> <p><b>First disabled law was signed in 1975</b>, giving monthly amounts to spread on any needs (from PA, to disabled material).</p> <p><b>Actual national law from 2005</b> n°102 <a href="http://goo.gl/QtMvUQ">http://goo.gl/QtMvUQ</a>, giving monthly amounts of PA hours.</p> <p>-New requests for PA must follow that second law.</p> <p>-Disabled persons who were already under the previous system are having the right to stay under 1975 law.</p> <p><b>Implementing decrees n. 2005 1591</b> and modified in June 2006 "<i>Prestation de compensation du Handicap Aide humaine</i>" (Personal assistance) :</p> <p><a href="http://www.legifrance.gouv.fr/affichTexte.do?cidTexte=JORFTEXT000000454080&amp;dateTexte=&amp;categorieLien=id">http://www.legifrance.gouv.fr/affichTexte.do?cidTexte=JORFTEXT000000454080&amp;dateTexte=&amp;categorieLien=id</a></p>
Is PA currently provided on a pilot basis?	NO
What is the total number of registered PA users in the country?	<p>There are 165,000 people into the '2005 system' for trimester 1, 2015</p> <p>And a more limited number of disabled people who wish to stay with the 1975 system because the new evaluation chart would downgrade (if not eliminate) their PA hours.</p> <p>They prefer staying away of some financial help improvements on building accessibility, car, or disability materials; to avoid being thrown away from the PA available in 1975.</p>
Has this number increased, decreased	Considering people had the choice to get or not the new system, the number is increasing, but this does not

<p>or stagnated (eg due to waiting lists) in the last 5 years?</p>	<p>necessarily mean that there are actually more people needing PA after 2005.</p> <p>Some people immediately switched to the new system, some other have waited for their next reassessment, and some renewed their previous rights.</p> <p>There is a global increase of 89% since 2010.</p> <p>The number can be decomposed in this way:</p> <p>Increased by about 22% each year from 2010 to 2012 because 2005 new PA legislation made eligible more people than the previous one.</p> <p>Increased by about 8% each year since 2013, with a slight decrease by 1% a year as most of the people eligible have already applied.</p>
<p>Does everyone, regardless of type of impairment, have access to PA?</p>	<p>NO</p> <p>Disabled persons cannot get support for some of their needs – those which do not fit evaluation charts.</p> <p><b>Mental disability</b> can only have 3 hours of PA, plus up to 6 hours of PA dedicated only to daily life needs.</p> <p><b>Blind and deaf people</b> are getting too limited monthly amounts, and they have to spread it between PA and disability material needs.</p> <p><b>Children</b> cannot get all the support available for adults. Parents are in the situation to choose between allowances depending on monthly spending on disability; or choose some PA hours without compensation on monthly spending on disability.</p>
<p>Does everyone, regardless of age, have access to PA?</p>	<p>YES, but there are still some inequalities.</p> <p>Disabled people under 65 years of age can get up to 36 hours a day in theory. But in reality it is undervalued. After 65 they may keep what is already evaluated. People who become disabled after 65 of age are following other rules.</p> <p>Amounts are far lower than disabled people's needs.</p> <p>There is also the issue that some people cannot get enough PA hours, while others are eligible to use certain amount of PA hours only because there have requested it.</p>
<p>Are there restrictions on what PA can be used for?</p>	<p>YES</p> <p><b>They can be used</b> for personal care, only one hour is granted for social activities.</p> <p><b>It does not include</b> cooking and household tasks, shopping</p>

	<p>for daily needs. These hours should be requested from the City Hall. However, they are not easily granted.</p> <p><b>Hours for treatments</b> must be nursing services financed by Social Security (creating complicated schedules for disabled people, as this kind of services are often provided at inconvenient time)</p> <p><b>Authorized care delegation</b> to PA is very hard to get as :</p> <ul style="list-style-type: none"> <li>• There is no budget for training.</li> <li>• Care delegation principle is not well understood by medical doctors, services and PA</li> </ul> <p><b>Increased PA needs during travel</b> are not considered. Disabled people must find an assistant who accepts a limited salary even working 24 hours a day.</p> <p><b>For working disabled people</b> PA rights are very limited. 156 hours each year at the maximum + exterior public organizations for €9000 to adapt workstation.</p>
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**CHANGES IN LEGISLATION/POLICY**

<p>Have there been any changes in legislation/policy restricting the use of PA in the last 5 years?</p>	<p>YES</p> <p>People who <b>renew</b> their <b>assessments</b> of 24 hours a day PA, have more and more trouble to get the needed PA hours. Disabled people who didn't have previously these full-time PA, most of the time are unable to fulfill these 24hrs needs even they need it.</p> <p>Public evaluation service tells they had overestimated the needs in the previous evaluation, as a justification.</p>
<p>Have any other limitations been introduced that prevent/restrict PA use in the last 5 years?</p>	<p>NO</p>
<p>If negative changes/restrictions have taken place in the last 5 years, what were the reasons (eg structural, financial etc.)?</p>	<p>There is an unofficial decrease of PA hours needs evaluation so government can limit the costs.</p>

<b>ELIGIBILITY ASSESSMENTS</b>	
Who carries out eligibility assessments for PA?	<p>Assessed by the local authority, each one of the 102 departments in the country has a MDPH (Departmental House of Disabled People), a structure created by the 2005 law.</p> <p>The role of the MDPH is to determine how many hours of PA service a disabled person needs. The sum can be paid directly to the disabled person or can pay directly PA bills. It's according to disabled people choice between services, direct payment or family assistance.</p>
How often are assessments repeated?	The MDPH decides how often there should be a reassessment and it should take place at least once every 10 years.
Is there a specific assessment tool that is used?	<p>The tool is a form of about 40 pages called GEVA (Guidelines of evaluation of compensation needs for disabled people). Department authority is encouraged to use it.</p> <p>As the form is too big and detailed, many departments don't really use it as observed by NGOs, although many of them are declaring they do.</p>
<b>FUNDING</b>	
How are PA services funded?	<p>Both national and local funding YES</p> <p>Funding of the services is very complicated as there are many stakeholders. Amounts are incorporated in the budget for disability, old people, from PA to material needs.</p> <p>Historically PA funds were distributed at the national level, but the funds have been mainly used for institutions (disabled or elderly). Following application rule, departments had to spend much money year after year, so in a few years they finance by their own what the state did at the opening of 2005's legislation. Nowadays PA funds are more and more unprofitable in departments; and government is taking every funds not used to deal with others expenses sectors.</p>
Is PA a means tested service?	<p>Yes, over a defined yearly income, disabled people must take in charge 20% on its own expense.</p> <p>Anyhow, the funds given for these both cases aren't sufficient to cover a few labour low required fees, individual must contribute to:</p> <p>Increased hourly wage for nights, weekends, statutory holiday. (1200€/year for people with H24 needs with PA</p>

	<p>outside family) Occupational health fee (100€/worker/year), increased wage during transportations, and for travel.</p> <p>Disabled people are often convicted by labour Courts because they are unable to pay for these charges.</p>
<p>What is the maximum number of PA hours per day/week that can be approved?</p>	<p>Up to 24 hours per day, exceptionally some disabled people have 26 hours or even up to 32 hours per day. The double assistance is for tasks such as lifting which require two persons.</p> <p>People who must go to the court to obtain the number of PA hours suiting to their needs, are succeeding their actions. Sometimes it takes years to get it.</p>
<p>What is the hourly rate that is funded?</p>	<p>3,67 €/h to 5,51 €/h for the family but maximum amount of €1100 each month.</p> <p>12, 49 €/h for direct hiring.</p> <p>13,74 €/h for proxy PA service (disabled is hiring, proxy is doing administrative job).</p> <p>17, 77 €/h for PA service with its own workers.</p> <p>A deaf person 374, 70 €/month</p> <p>A blind person 624, 50 €/month</p>
<p>Are direct payments/personal budgets available for funding PA?</p>	<p>YES</p> <p>Choosing between bills paid directly by authority, or getting the money on their bank account to pay their proxy service or the personal assistants for people who choose direct hiring. Every expense must be justified.</p> <p>Authorities are trying to make people choose to use some prepaid accounts dedicated to PA wages.</p>
<p>What is the total number of direct payments/personal budget holders in the country?</p>	<p>Information unavailable</p>
<p>Are family members allowed to be paid as PAs?</p>	<p>YES with limited wages (only thought as the compensation)</p> <p>Depending on unclear criterion if the disabled people need many hours of PA; family is allowed to be paid as full-time job (means legal hourly wage).</p> <p>If the need of PA hours is low; family is only allowed to get a compensation (means small hourly wage).</p>

<b>PROVIDERS AND SUPPORT</b>	
Is there a choice of providers of PA services?	YES: PA service, proxy service, direct hiring, family
If PA can be provided by user-cooperatives, do they have to be accredited?	YES
Are PA users provided with training on how to manage their assistance?	NO A minority of NGOs (Gré à Gré for example) is currently developing informal experiments on peer counselling, currently developing training program in partnership with public organizations.
Are people with intellectual disabilities allowed to manage their own assistance?	Yes they are allowed except if they are under guardianship or curatorship, in this case the curator can be the employer of PA.
Are support services such as peer support/peer counselling/IL training provided by user organisations funded by the state or the local authority?	A very little bit at local level - if disabled people NGO are taking initiative of organizing training and convincing authorities to help them budget.  There are a few experiments but it's a very confidential scale.

## ***PART 2: ADDITIONAL INFORMATION***

Please provide <b>background information about the introduction of PA into legislation/policy</b> (which actors were involved in	2005 Law: <a href="http://www.legifrance.gouv.fr/affichTexte.do?cidTexte=JORFT-EXT000000809647">http://www.legifrance.gouv.fr/affichTexte.do?cidTexte=JORFT-EXT000000809647</a> Decret on n. 2005 1591 and modified in june 2006 "Prestation de compensation du Handicap Aide humaine"(Personal assistance): <a href="http://www.legifrance.gouv.fr/affichTexte.do?cidTexte=JORFT-EXT000000454080&amp;dateTexte=&amp;categorieLien=id">http://www.legifrance.gouv.fr/affichTexte.do?cidTexte=JORFT-EXT000000454080&amp;dateTexte=&amp;categorieLien=id</a> - Time frame of the development of the legislation: from 2002 to 2005 but the revision process of 1975's legislation started
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<p>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>already before.</p> <ul style="list-style-type: none"> <li>- Development of the type of legislation: the general type of legislation includes all aspects of the life of people with disabilities.</li> <li>- Role of IL in the lobby for legislation reform: The IL principles at the time were mainly put forward by the future CHA members.</li> <li>- Ideological conflicts in the lobby process: The main ideological conflicts rested in the differences between organizations, managing institutions and services and those managing no institutions and services.</li> <li>- Is the legislative in accordance with ENIL IL principles: Only in part as P.A is not granted based on the assessment of the real needs of people.</li> </ul>
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<p>Are there any current <b>challenges</b> in implementing the PA legislation/policy?</p>	<p>Yes since 10 years (2005 law) associations are hardly working to make every restriction we talked about in this form cease. But nothing really changes as long it isn't pretty separated.</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>Disabled people were already empowered before actual PA law was voted in 2005.</p> <p>There was a previous law for PA in 1975 obtained after first disabled lobby campaign, but the means were very limited. People couldn't have 24 hours a day but there were able to get a small amount to spread at will between on their PA need, and their disabled material needs.</p> <p>2005 PA law led to significant PA financing improvements. Since the legislation the empowerment has increased as disabled have better daily conditions! Getting 24 hours (36 for a few) only to be spent for PA. Amount for material needs (transports, refurbishments of interior, car adaptation) is separated into the disability compensation plan.</p>
<p>Is PA used in the process of <b>de-institutionalisation</b> (to help people leave institutional care)?</p>	<p>No</p> <p>Government is increasing the number of available places institutions for people with multiple disabilities. Moreover in France many institutions are being run by disabled people associations. As they are lacking of budget, they do what they can to raise much more funds each year. They have no interest on money going to independent</p>

	living.
Was any research carried out in the country on the <b>costs</b> of PA? If yes, please provide links or attachments.	No one is interested on carrying out researches, as the topic doesn't seem to have a real interests for people with the necessary skills.
If <b>family members</b> are allowed to work as PAs, is this considered problematic or beneficial?	

*Note: A change of legislation in France was implemented in April 2016, affecting the provision of personal assistance. You can read more [here](#).*