

## ENIL Personal Assistance Survey

**Country/region:** United Kingdom

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### PART 1: KEY INFORMATION ABOUT PERSONAL ASSISTANCE

LEGISLATION/POLICY	
Is there legislation covering personal assistance (PA)? yes	YES  National England Care Act 2014  Health Act 2009  National Scotland Social Care (Self Directed Support) Act 2013  National Wales Social Services and Well-Being (Wales) Act 2014  National Northern Ireland Health and Social Care Reform (NI) Act 2009
Is PA currently provided on a pilot basis?	NO
What is the total number of registered PA users in the country?	Accurate numbers are not kept. It is about 250,000.
Has this number increased, decreased or stagnated (eg due to waiting lists) in the last 5 years?	Increased
Does everyone, regardless of type of impairment, have access to PA?	YES in theory, although in practice research suggests people using mental health services have less access than other groups.

Does everyone, regardless of age, have access to PA?	YES
Are there restrictions on what PA can be used for?	<p>YES</p> <p>A PA can only be used to meet assessed needs. Some local authorities try to impose restrictions on how a PA can be used for example only for personal care but the legislation is clear that a PA can be used to meet assessed needs in any way that best meets those needs.</p>
<b>CHANGES IN LEGISLATION/POLICY</b>	
Have there been any changes in legislation/policy restricting the use of PA in the last 5 years?	<p>Yes</p> <p>The closure of the centrally funded Independent Living Fund (ILF). This closed to new users in 2010 on June 30<sup>th</sup> 2015 it was closed to all ILF users, despite a strong campaign by DPAC against closure. All ILF users funds in England (estimated to 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 in some cases night time support will be removed-all will affect PA use. Scotland and Northern Ireland will retain a central fund through the newly created ILF Scotland. Wales will have cash transferred to local authorities. We have no guarantees that funding will continue to be provided after March 2016.</p>
Have any other limitations been introduced that prevent/restrict PA use in the last 5 years?	<p>YES</p> <p>In the last 5 years the money available for care has reduced resulting in tighter eligibility for services resulting in many disabled people no longer being eligible for support, in instances where they are evidence shows that 15-minute visits from agency workers are being used increasingly</p> <p><a href="https://www.unison.org.uk/news/article/2014/12/15-minute-home-care-visits-in-england-on-the-rise/">https://www.unison.org.uk/news/article/2014/12/15-minute-home-care-visits-in-england-on-the-rise/</a></p>
If negative changes/restrictions	Financial

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?	Local Authorities
How often are assessments repeated?	In theory every 12 months
Is there a specific assessment tool that is used?	NO Every local authority uses a different assessment tool although there are guidelines in the legislation after assessment funds are then subject to a Resource Allocation System (RAS) process that also differs for each local authority to determine an indicative amount of support.
<b>FUNDING</b>	
How are PA services funded?	By the state: NO By the regional or local authority: YES Both: NO  N.B the state allocates local authority funding. Funding fell by £4.6billion (31%) over the past 5 years, a further £1.1billion will be cut for year 2014/15 to local authorities. <a href="http://www.publicfinance.co.uk/news/2015/06/social-care-funding-cut-third-2010-adass-survey-finds">http://www.publicfinance.co.uk/news/2015/06/social-care-funding-cut-third-2010-adass-survey-finds</a>
Is PA a means tested service?	YES  Most people have to contribute to the cost of having a PA. Everyone has to have a financial assessment that decides how much they have to contribute. The only exemption is for people with very high support needs who get a personal health budget who do not have to contribute anything.

What is the maximum number of PA hours per day/week that can be approved?	24/7
What is the hourly rate that is funded?	This varies from one local area to another.
Are direct payments/personal budgets available for funding PA?	YES
What is the total number of direct payments/personal budget holders in the country?	Over a million personal budgets with about 10% taking their personal budget as a direct payment.
Are family members allowed to be paid as PAs?	NO No, not if they live in the same house.
<b>PROVIDERS AND SUPPORT</b>	
Is there a choice of providers of PA services?	YES  Local authorities contract with local organisations to provide PA support services. In some local authorities these organisations are run by disabled people, in other areas not. However, many Local authorities are pushing people towards what is called telecare (i.e. use of technology rather than PA employees as this is a cheaper option) and incontinence pads for continent disabled people as a replacement for overnight support.
If PA can be provided by user-cooperatives, do they have to be accredited?	NO
Are PA users provided with training on how to manage their assistance?	It depends on what the disabled person employing the PA wants to do. There are training schemes but disabled people don't have to use them. Most people train their own PA.

Are people with intellectual disabilities allowed to manage their own assistance?	YES, some do, but in many cases the PA is managed by family members.
Are support services such as peer support/peer counselling/IL training provided by user organisations funded by the state or the local authority?	Local authority, but such funding is becoming less and less and user organisations are not given priority, many have lost funding for such activities completely due to cuts at local authority level and local authorities seeing such activities as non-essential.

## PART 2: ADDITIONAL INFORMATION

<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>The introduction of independent living in the UK is probably well known but here is a summary:</p> <p>1970s – disabled people drew inspiration from the U.S.  First centre for Independent Living set up 1984  First example of employing PA is John Evans 1984 using funding from his local authority as a direct payment.  1993 UK government declared direct payment to be illegal.  Campaign by disabled people to make direct payments legal resulted in Community Care (Direct Payments) Act 1996.</p>
Are there any current <b>challenges</b> in implementing the PA legislation/policy?	<p>The biggest challenge is lack of funding.</p> <p>In addition, some of the reasons why employing your own PA is becoming less and less feasible as an option for disabled people include the following:</p> <ul style="list-style-type: none"> <li>- Blanket hourly rates not in line with the living wage making it impossible to recruit</li> <li>- No choice in eg who to use for payroll or support</li> </ul>

	<p>to manage your Personal Budget (this is now challengeable under the Care Act).</p> <ul style="list-style-type: none"> <li>- Retrospective or extremely short notice decisions made by local authorities to reduce their hourly rates leaving disabled people out of pocket</li> <li>- Unmanageable monitoring processes</li> </ul>
<p>Has the legislation/policy on PA led to <b>empowerment</b> of disabled people, setting up of CILs or cooperatives etc.?</p>	<p>Yes, many CILs set up after the 1996 Act. Many have since closed because of lack of funding.</p>
<p>Is PA used in the process of <b>de-institutionalisation</b> (to help people leave institutional care)?</p>	<p>No, rather we are looking at a very likely process of people being re-institutionalised due to cuts.</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>Yes, but it was so long ago that it is now out of print and no longer available. There are stats for England only showing drop in 'community care' since 2008 by 29% this includes direct payments.</p>
<p>If <b>family members</b> are allowed to work as PAs, is this considered problematic or beneficial?</p>	<p>Family members can be PAs but only if they don't live in the same house as the disabled person. This can work well for people from some groups such as ethnic minority communities.</p>