



# Personal Independence Payment (PIP) Consultation

## Introduction

At the end of 2010, the Government published proposals for replacing Disability Living Allowance (DLA) with a new benefit called Personal Independence Payment (PIP).

The Government did this because they consider DLA to be old fashioned – it was introduced in 1992 and has not changed since. They also aim to reduce the number of people claiming the benefit by 20% by 2015/16 so saving on expenditure. The Government wants to assess an ‘individual’s ability to participate in society, as a proxy for the impact of disability and the extra costs disabled people can face’, rather than focus on the activities that people cannot do. Reflecting this, they believe the PIP has a better and more modern perspective on disability and that it will;

- Take notice of how impairments affect an individual rather than just focusing on the impairment itself
- Take account of all impairment types fairly
- Assess variable and fluctuating ability accurately.

The new benefit will begin to be brought in for people of working age (16-64) in 2013. Those already receiving DLA will be reassessed to see if they are entitled to receive PIP. (According to the February 19<sup>th</sup> Work and Pensions Select Committee, it seems possible that the implementation of PIP ‘will be limited initially to a few thousand new claims per month in one geographical area’.) People under 16 or over 64 receiving DLA will continue to receive it as the government has no current plans for changing DLA for these groups of people.

## Consultation process

There have been several stages of consultation, beginning with a set of questions, followed by a draft assessment criteria document. Although learning disability organisations have been consulted it is not clear how many family carers have.

Up until 30<sup>th</sup> April 2012, organisations, individuals and others (including yourselves as family carers) are being asked for feedback on the second draft criteria, which have already been improved through feedback on the earlier version. The Department of Work and Pensions (DWP) is mainly asking for views on the weighting given to each descriptor in the eleven activities on which an individual will score points to show if they qualify for PIP, and at which level of entitlement. This is explained in more detail below. Definitions of terminology are also being consulted on.

If you would like to give your views, we explain how to do this at the end of this document. We are enclosing the DWP Consultation Questions, PIP assessment activities and descriptors and Draft Regulations to help.

## **DLA: PIP similarities and differences**

One main difference between the two benefits is that for the PIP assessment, in addition to completing a form, nearly everyone will be required to attend a face to face assessment, with few exceptions. At the moment, the documents say that a minimum of 7 days' notice will be given for someone to attend an assessment. Another difference is that more regular reviews of entitlement to the benefit are planned and claimants will be asked to notify the DWP of any changes to their situation. This is because it is known that some people who receive DLA may have done so for years although the condition they originally applied for no longer affects them in the same way.

DLA and PIP have some similarities; both have two components, a daily living component and a mobility component. PIP however, will have just two levels of each component; standard and enhanced. For the new benefit you need to score at least 8 points to receive the standard level (described as limited ability), and at least 12 points to receive the enhanced level (severely limited ability), for either daily living or mobility (or both), based on how you carry out particular activities.

## **PIP assessment activities and descriptors**

The assessment is based on 11 different activities. Activities 1-9 relate to the daily living component and 10-11 relate to the mobility component:

1. Preparing food and drink
2. Taking nutrition
3. Managing therapy or monitoring a health condition
4. Bathing and grooming
5. Managing toilet needs or incontinence
6. Dressing and undressing
7. Communicating
8. Engaging socially
9. Making financial decisions
10. Planning and following a journey
11. Moving around

Each activity has a number of statements about what is needed for someone to be able to do the activity. They are called descriptors. Each descriptor has a number of points which are added up to work out a person's eligibility for PIP. The more limited a person's ability at doing the activity the more points are scored.

To get points, you need to satisfy descriptors for more than half of the time (considered over a 12 month period).

## **Terminology**

Individuals need to consider how they carry out an activity in relation to particular terms; the DWP is also asking for views on this terminology and if it should be

included in the detail of the activity descriptors. These terms indicate whether the activity can be done;

- *Reliably* - to a reasonable standard
- *In a timely fashion* - in less than twice the time it would take for an individual without any impairment
- *Repeatedly* - completed as often during the day as the activity requires – considering cumulative effects of symptoms such as pain and fatigue; whether completing the activity adversely affects the individual's ability to subsequently complete other activities
- *Safely* - in a fashion that is unlikely to cause harm to the individual, either directly or through vulnerability to the actions of others; or to another person

It is important to be aware of the meaning of three other words used in the assessment for PIP and how they relate to the individual when doing an activity;

- *Supervision* - another person needs to be there the whole time an activity is being done 'to prevent a potentially dangerous incident occurring'
- *Assistance* - another person needs to be there to help the activity to be done, but does not need to be present the whole time
- *Prompting* - does not require the presence of another person, but the prompting could be done from a distance, for example by a telephone call. It must be essential for the activity to be done.

## **PIP and people with learning disabilities**

There does seem to be more focus on considering the needs of people with a learning disability than there has been before. The wording used for the communication activities shows consideration of how a person with a learning disability may be affected by communication difficulties. For example, after feedback from an earlier consultation, the communication aspect of assessment was split into two activities; 'communicating' and 'engaging socially', which seems more appropriate than the previous one activity 'communicating with others'.

Although some of the PIP assessment activities can be related more easily to people with a learning disability than the activities assessed for DLA, there is a feeling from much of the documentation so far that the tests will be more strict, to enable the government to meet their target to reduce the number of people receiving the benefit. In fact, twice in the documentation, it has been said that 'individuals with learning disabilities appeared to be over-scored' by the criteria. This is your chance to give an opinion on the appropriate weighting of points for the descriptors in relation to your family member who has a learning disability!

## **Responses to consultation so far**

The Government has tried to include people with disabilities throughout the consultation process and in order to do this, asked specific groups of people to be involved in the testing of assessments, including groups of people with a learning disability.

Some of the more positive changes made so far in response to feedback:

- Wording has been changed to make it clearer and more understandable which will hopefully reduce the scope for individual assessors' interpretation
- It has been recognised that people should not be expected to live on microwave ready meals, so the 'Preparing food and drink' activity now relates to preparing fresh food
- 'Overwhelming psychological distress' no longer needs to have an effect for several hours after the activity in order to be taken into account
- Use of aids and appliances are considered – as PIP is 'based on an individual's level of participation in society...if individuals are participating well with the help of aids or appliances...this should be reflected'. Aids and appliance usage do, however, attract a score, so they are not entirely ignored
- When someone has to attend a face to face assessment, they can take another person such as a family member, friend, carer or advocate with them to the assessment if they will find it helpful.

## **Your views on scores and their weighting**

As mentioned earlier, the Government is now asking specifically for feedback on the weighting given to descriptors of activities. There are two elements to the allocation of points which we question.

### **1. The hierarchy of scores**

Do you agree with the order and scoring of descriptors? For example: Activity 10; *Planning and following a journey* gives 5 descriptors varying in weighting. There is one descriptor which gives the individual 15 points, automatically entitling them to the enhanced rate of the mobility component (*'Needs either - i. supervision, prompting or a support dog to follow a journey to a familiar destination; or ii. a journey to a familiar destination to have been planned entirely by another person'*). The descriptor preceding this *'cannot follow any journey because it would cause overwhelming psychological distress to the individual'* scores only 10 points despite the comment *'For example: may apply to individuals who are unable to leave the home at all - should this also be given enough weighting to score the enhanced level of mobility component? Thinking of someone with a learning disability, are descriptors in the correct order of importance and is the scoring appropriate?*

### **2. Most usual or average?**

Generally to score on any descriptor, it must apply for at least half of the time. However, if there are several descriptors that together add up to half or more of the time, the descriptor that applies most of the time will be taken and the individual will score the weighting of that descriptor. Would it be fairer to average the weighting of these descriptors? By not doing this, someone could potentially miss out on up to 13 points which could have a huge bearing on the assessment of their entitlement to benefit, or the rate at which they receive it.

One example of this is Activity 8, *Engaging Socially*. Let's consider a person who has behaviour that sometimes can be challenging. They may be able to *'engage socially unaided'* (A - 0 points) for the majority of the time, but sometimes they *'cannot*

*engage socially due to such engagement causing (ii) the individual to exhibit uncontrollable episodes of behaviour which would result in a substantial risk of harm to the individual or another person' (D – 8 points). In this case for this activity, they would score 0 points. If the score was calculated as an average, they would score 4 points towards their final score. You may be able to spot other examples where using only the most usual situation to score an activity would impact greatly on the level at which a person receives the benefit, or indeed if they receive it at all.*

Consultation question 6 asks for views on how the DWP is dealing with fluctuating conditions; the example above shows that a fluctuating condition is not taken into account, because of the way in which the weighting is set and the scores are calculated.

## **Other issues**

How the questions are asked will impact on how they are answered. It is unclear at this stage how questions will be asked on the forms that people have to complete – we are currently only able to see the activities from the assessor's side.

The DWP has decided to contract different organisations in four parts of the country to carry out the PIP assessments. There are pros and cons to this; potentially there will be more room for different interpretation of assessment criteria by different companies, but also it reduces the potential for a national repeat of the mistakes which were widely documented about the Work Capability Assessments for Employment and Support Allowance by ATOS Healthcare.

The report from the Work and Pensions Select Committee in February this year has advised that companies are only paid for 'right first time' assessments to avoid unnecessary expenditure of public money, through paying again for re-assessments and appeals. So far the consultation documents have not addressed the appeal process which is important to consider and we wait for more information about this.

## **Giving your views**

We think it is very important for the Government to hear as many views on this consultation from as many people as possible, particularly the views of family carers. If you would like to have your views heard, we give details of where to send your response at the end of this document. If you would like to, we would be grateful if you could also send us a copy of your response so we can put everyone's views together with ours and respond as an organisation. The details of how to send us your responses are also below.

When reading through the consultation documents, it is important to do so with your relative in mind and to consider how the proposals could affect them if they were applying for the benefit, or being reassessed under the new rules.



Responses to the current consultation are expected by 30th April 2012. If you would like to send your response to us, please could you do so by 20<sup>th</sup> April 2012 so we can collate the responses with our own.

To help you form your own opinion on the consultation please refer to the enclosed:

- List of activities with the proposed weighting for the descriptors
- Consultation questions
- Draft Regulations

There are some other useful and interesting documents you might also want to look at for further reading:

- Proposed PIP Regulations; An Unofficial Simplified Summary of the Second Draft Regulations. [www.wearespartacus.org.uk](http://www.wearespartacus.org.uk)
- Personal Independence Payment – frequently asked questions 19 January 2012. [www.dwp.gov.uk/pip](http://www.dwp.gov.uk/pip)
- Personal Independence Payment: assessment thresholds and consultation January 2012. This document gives some case studies of how the descriptors and scores will be applied. [www.dwp.gov.uk/pip](http://www.dwp.gov.uk/pip)

There have been several formats of the draft criteria produced, including large print, audio and easy read versions which can all be downloaded from [www.dwp.gov.uk/pip](http://www.dwp.gov.uk/pip).

Responses direct to the Department for Work and Pensions:

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