

Personal Independence Payments: feedback on assessment thresholds and activity descriptors

Response by Advice Services
Coventry to PIP Assessment
Development Team, DWP

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Introduction

Who are we?

- Age UK Coventry
- Coventry Benefits Advice Line
- Coventry Cyrenians
- Coventry Refugee Centre
- Coventry & Warwickshire Family Mediation
- Coventry Citizens Advice Bureau
- Coventry law Centre
- Midland Heart
- Holbrooks Community Care Association
- Coventry Student Union Advice Centre
- Willenhall Advice Centre
- Wood End Advice & Information Centre

What do we do?

The Advice Services Coventry (ASC) partnership was formed in 2005

ASC is a partnership of agencies that are classified as providers of independent advice services.

The overall objective of ASC is to ensure the people of Coventry are aware of their rights and have knowledge of where to get help and advice on a range of issues including: Community Care, Debt, Discrimination, Employment, Housing, Immigration, Public Law and Welfare Benefits.

ASC seeks to ensure that those who are vulnerable and/or socially excluded should have ready access to advice services and the support necessary to use those services to meet their needs.

For more information on any aspect of this response, please contact:

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PIP assessment activities and thresholds

This response takes the form of direct comment on questions posed in the consultation document followed by specific comment from ASC representatives on issues arising from the application of thresholds to listed case studies (see appendices).

Question 1: What are your views on the latest draft Daily Living Activities?

No reference is made to moving around indoors, particularly up and down stairs. Also, no reference is made to a claimant's capacity to sleep. Both activities are essential aspects of a claimant's 24 hour day and generate significant associated care needs. They should both be added.

The inclusion of 'making financial decisions' is positive (but see later comments for constructive amendments).

Question 2: What are your views on the weightings and entitlement thresholds for the Daily Living activities?

With each activity, gradations of severity generally work but some slight adjustments should be considered (see below). Weightings between activities need adjustment. Needing someone to ensure medication is taken safely is just as important as someone ensuring you can eat or drink. Not being able to manage incontinence at all is a devastating physical and mental problem. Activities 1,2,3 and 7 are life threatening issues if not confronted effectively, activity 5 is quality of life destroying and activities 4,6,8 and 9 are substantially debilitating.

Specific adjustments to be considered should include the following: 8d) change 'substantial risk of harm' to 'identifiable risk of harm'; 9c) change 'needs prompting to make financial decisions' to 'needs assistance to make simple financial decisions' (score 4); and 3b) should score 8.

Question 3: What are your views on the latest draft Mobility activities?

No reference is made to 'moving around indoors' (especially up or down stairs or at night), or 'outdoors on difficult terrain'. Both everyday activities should be reflected in the activities listed.

Question 4: What are your views on the weightings and entitlement thresholds for the Mobility activities?

Weightings between activities are even. This is fair. Within each activity, some adjustments should be considered. The scoring scheme for activity 10 should be amended as follows: 10d) should be 12 pts, not 10; and, 10e) should be 12 pts, not 15. For activity 11 the following amendments should be considered: 11c) should be removed as it is non-sensical; the point score for 11d) should be 12 pts, not 10; and

the score for 11f) should be 12 pts, not 15. References to wheelchairs or motorised scooters should include walking frames.

In all these activities, no explicit reference is made to completing tasks safely, reliably, repeatedly or in a timely fashion. Though this issue is dealt with in a later question, a separate barrier to task completion is still wrongly ignored; namely, being able to complete a task 'without severe pain/discomfort'. This should be included as a legitimate barrier to task completion.

Question 5: What are your views on how the regulations work regarding benefit entitlement?

This is clear up to sub-paragraph 4 parts c and d. Part c does not allow for a situation where a claimant has a health condition which affects one descriptor for less than 50% of days of the required period but the effect on that descriptor is cripplingly intense. The condition may be constant at a low level but fluctuating in intensity, or effectively non-existent for much of the time but unpredictably cripplingly intense.

Part d states the claimant is to be assessed as if wearing or using any aid or appliance which is normally worn or could be reasonably be expected to worn or used. What is 'reasonably expected'? Aids/appliances may be too expensive to buy, too hard to obtain, too painful to use frequently, too unreliable to use frequently or generate counterproductive physical or mental side-effects. It is not fair, and possibly discriminatory, to expect all claimants to have or use aids/appliances, even if they could be seen by others as helpful. Their health conditions should be treated 'in the raw' as they will spend much of their days in this state.

Question 6: What are your views on how we are dealing with fluctuating conditions?

See question 5. Further, the regulation is complex and could be simplified by stating that a descriptor must be met for a 'significant period of time'; significance being a balance between frequency of effect and debilitating intensity of effect. A qualitative judgement could then be made, and defended, case by case for fluctuating conditions.

Question 7: What are your views on the definitions of 'safely', 'timely', 'repeatedly' and 'in a timely manner'?

(see note after question 4). It is imperative for the sake of justice being seen to be striven for in this form, that these stipulations, and one reflecting 'without severe/chronic pain/discomfort', be clear in the questions, either on every separate question or, more practically, as a highlighted note at the beginning of the first section of questions. Without a direct reference, implicit assumptions will be missed and the form inadequately completed.

Furthermore, it should be stressed in any preamble that the claimant's situation must be described as if he/she is alone and the task at hand cannot be avoided.

Question 8: What are your views on the definitions in the regulations?

According to the list of definitions, 'cook' means 'heat food', not make a meal. This implies ready-meals with low or no nutritional value rather than meals with fresh ingredients. 'Cook' should be re-defined as something like 'assembling, manufacturing or creating a meal'; ie something that alludes to a potentially complex exercise rather than just putting a ready-meal in a microwave oven. The reference to 'at or above waist height' is bizarre and unnecessary. 'Groom' includes washing hair but not drying it. This latter activity is integral and may be implied but requires explicit reference as it has consequences for how a claimant's care needs can be described and scored. Finally, 'take nutrition' should include 'without undue mess' (or similar words) as this reflects further potential physical activity required in essential clean up which impacts on any description or scoring of a claimant's care needs.

Question 9: Do you have any other comments on the draft regulations?

There are specific issues to be taken into account around the requirement to provide information, the possible requirement to attend either face-to-face consultations or telephone consultations, the definition of 'good cause' to prevent automatic negative determinations, and the re-determination of claimant abilities.

Firstly, claimants are not always in full control of their own medical or other information. This is provided by GPs, hospital specialists, and other medical or care services (public or private). The claimant should not be held responsible for their inability or inefficiency to provide information requested in a timely manner. Even where the claimant is practically able to obtain a medical report, medical agencies, particularly GPs/specialists may make unreasonable charges for such reports. The claimant may not be able to afford supportive evidence. Vulnerable claimants, mentally or physically impaired, simply may not understand what is required of them or be too unreliable to respond effectively to such requests.

[It is important to note here that ESA reports should not be used in any PIP decision-making, whether favourable or not, as the purpose of such forms is to assess a claimant's capacity for work; not relevant to a PIP application].

Secondly, claimants - especially physically and mentally vulnerable ones – are often in no position physically to attend face-to-face consultations by the very nature of their health conditions; attendance may be debilitating, dangerous or life-threatening. They, whether for physical health, mental health, or cognitive impairment reasons, are also poor advocates of their own causes tending to under-estimate their own conditions, in what may seem as a casual conversation, by not recognising the true meanings of questions put to them. Further, telephone consultations discriminate against the hard of hearing, the inarticulate, those with learning difficulties and those for whom English is not their preferred language. Passing a test and receiving a public entitlement should not be dependent on how subjectively impressive or inarticulate the claimant is about their condition(s). This is fundamental.

Thirdly, the determination of 'good reason' why non-compliance should not be automatically followed with a negative determination allows no practical reason

outside the claimant's state of health or disability. The availability or cost of suitable transport (for those with severe mobility problems), the availability or cost of adequate childcare, or the absence of a working telephone, and so on can all impact on the capacity of a claimant to, for example, get to a face-to-face consultation or engage in a phone consultation. None of these can be held to be the sole responsibility of the claimant.

Both these situations assume the claimant has a fixed address and clear and reliable channels of communication with the DWP. This is not a fair assumption to make. Acceptable mitigating circumstances need to be broadened.

Lastly, the issue of what triggers a re-determination of a claimant's abilities needs to be clarified; particularly, any predetermined frequency which may either border on mental harassment or simply be unnecessary (eg claimants who are incurable). Under current law, claimants can be prosecuted for not disclosing changes in circumstances that may materially affect their entitlements. Why is this not reason enough for re-assessment to be initiated by claimants only (other than reviews taken in a random sampling form or precipitated by information about possible fraud) ?

These responses address the questions posed from the perspectives of social justice and administrative simplicity; being steadfast in the view that the design, delivery and operation of the new benefit must be seen from the disabled claimant's point of view and the experience they will be exposed to. We see the primary purpose of any changes as being an increased ability to capture the experiences of legitimate claimants, not to find ways of excluding possibly illegitimate claimants. Successful applications should not be dependent on how articulate or 'street-wise' the claimant is and, conversely, applications should not be undermined by factors not under the control of vulnerable claimants. Assessments should assume claimants are telling the truth unless they have evidence to the contrary, not assume they are liars to be trapped by 'clever' questioning.

Appendix 1.

From: XXXX Law Centre

PIP assessment thresholds consultation on the criteria

Question 1

The inclusion of the three new activity areas of Communicating, Engaging Socially and Making Financial decisions is welcome and assists to ensure that PIP has a more comprehensive coverage of the effects of disability. However the Engaging Socially activity is too heavily reliant on receipt of professional support. In the current financial climate this type of service is oversubscribed and consequently not available to many who require it and would benefit from it. It would be preferable to broaden the definition of social support to enable the very valuable support provided by carers, family members and friends. It is also regrettable that this activity appears to take a narrow view of relevant social activities which is out of step with current approaches and aims enshrined in the Community Care approach. This mismatch will inevitably lead to situations where assistance that is needed with social activities rightfully encouraged and promoted within Independent Living is not recognised but the benefit which is used in part to fund the Independent living. The opportunity needs to be taken to resolve this underlying conflict between the stated objectives of different Government departments. The progress made as a consequence of the Fairey/Halliday decisions which took a broader view of social activities to include hobbies should be reflected in the descriptors. A renaming of this activity to Social Activities and a change in the wording of the descriptors to include relevant activities would enable this objective to be achieved and would overcome the issues identified above.

There is also a need for additional activities to be included to cover the areas of fits and loss of consciousness as well as falls, movement inside the house and the risk of suicide. This omission will deny many with very serious conditions access to PIP. People who experience these problems are often at considerable risk of injury and indeed in some cases of loss of life. These claimants and their carers have a strong moral case for continuing to be able to access a disability benefit to meet the additional costs caused by their conditions which will enable them to make good through private provision the loss of home care and supported living arrangements affecting many in this group. A change in this area is also required to ensure continuity of assistance with claimants suffering from

the same conditions who reach their 16th birthday who will lose entitlement at age 16 under the current proposals.

Question 2

Activity 3 Managing therapy or monitoring a health condition is the activity which according to guidance is intended to be the main replacement for the current supervision test within DLA. The points awarded for descriptors in this activity are too low relative to the significance of assistance in this area to ensure overall safety and functioning. The range of points scored should be increased to enable those needing prompting or assistance for over 14 hours to score 12 points with proportionate increases for the other descriptors within this activity to bring them in line. The persons in case studies 4 and 5 have epilepsy and both have scored no points under this activity as it is currently phrased. Awards of DLA care component can be anticipated for both. I would recommend that it is made more explicit that this descriptor is intended to cover loss of consciousness and suicidal thoughts.

Questions 3 and 4 Moving Around

There is an urgent need to increase the points allocated to this activity. As it currently stands only those who cannot walk at all or who need a wheelchair within 50 metres will score 12 points and be able to access enhanced PIP mobility. Access to this rate should be available for those in Descriptors C and D which should therefore be increased to 12 points each with proportionate increases to other descriptors within this activity.

Question 6

The fluctuating conditions approach seems reasonable but I would suggest the need to take a broader approach of alternatively over half the days in the week or days in the last month. Most claimants will in reality be unable to accurately allocate the number of days from the past 12 months to each of the descriptors. This will generally not be clear from records available elsewhere and also does not lend itself to being accurately gauged at the medical assessment. More flexibility could avoid the need for costly and time consuming appeals on this point.

Question 7

I consider that safely, timely, repeatedly and in a timely manner should be included in the detail of the descriptors. This will ensure that these issues are more to the forefront and that claimants themselves are aware of them as well as medical assessors. Currently the similar provisions applying in ESA are not well known and their significance is overlooked by ESA medical assessors leading to many unnecessary appeals.

Appendix 2.

From: a MacMillan-sponsored Bureau Adviser

Hi XXXX

A few things spring to mind....

P23. Notice the introduction of “she has to use her left hand to type”. This is an ESA50 question. Ability to undertake work related activities is not part of the assessment for PIP.

There is no case study for a client who is actually being treated for cancer at the time they make a claim for PIP.

Despite reference to fluctuating conditions in the introduction, there is no case study to demonstrate how this would be assessed. Can the DWP please provide an example?

P29 and 30, the case studies about customers with mental illness are unrealistic. It is very unlikely that someone with a diagnosis of depression would be under the care of the psychiatrist. The case studies seem to be suggesting that people with mental health problems will have a low level of need.

There are no case examples of customers with severe mental illness such as Schizophrenia and Bipolar Affective Disorder. The latter condition would make an ideal worked through example of a fluctuating condition where there are some care and mobility needs most of the time but more unpredictable severe episodes where greater care and mobility needs can be present.

A case study of someone with MS or Lupus would also demonstrate how fluctuating conditions might be assessed.

Hope this is helpful.

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Appendix 3.

From: a local benefits advice line

Hi XXXX,

This is very much a last minute response..... I've only been able to draw on the case study decisions.

My comments in brief:

Q2 - the weightings and entitlement thresholds:

In Case Study 4, the failure of the benefit to consider "monitoring of a health condition" to recognise unstable epilepsy is highly perverse. I had only ever interpreted this descriptor to include monitoring because of the very high level of risk and chance of injury or fatality

In Case Study 5: there is no reference to disorientation nor monitoring of behaviour after a fit and no recognition of the increased costs to the claimant of, for example, ready-prepared meals (currently about £5.00 from Wiltshire Farm Foods), demonstrating again that "monitoring of a health condition" has been ignored

The descriptor covers both the monitoring and "taking action advised by a healthcare professional" - surely this should include care and safety advice, even if from a hospital booklet?

In Case Study 6: I'd query award of standard mob where claimant would need wheelchair to get any further than 20 steps

In Case Study 14: there is the failure to acknowledge that claimant only "cooks for her children" or that the structure of the household is a factor in her ability to care (if the children weren't there, would she self-neglect?) Would these issues count as "fluctuating"?

Thanks

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