

Papworth Trust's Response to the Personal Independence Payment **Second Draft Criteria Consultation**

Background

Papworth Trust is a disability charity and registered social landlord, whose aim is for disabled people to have equality, choice and independence. Papworth Trust helps over 20,000 people every year through a wide range of services including employment, vocational rehabilitation, housing and personal support.

We are pleased to see that the Department has produced a second draft of the Personal Independence Payment (PIP) which makes several improvements to its first draft. Papworth Trust surveyed over 2,200 people on the first draft criteria and has again engaged with its clients to provide feedback and suggestions for the second draft criteria to ensure that it is fit for purpose. To inform this response we held a consultation event in conjunction with DWP in April 2012 attended by 45 disabled people, carers and other disability organisations. Because of our broad focus, a range of conditions and impairments were represented by the attendees at our consultation event. Positive feedback was received from many people who were grateful to receive clarity on the criteria and assessment from DWP, which reduced anxieties and dispelled myths. **Going forward, Papworth Trust urges the Government to ensure that it produces clear communications on the introduction of PIP which it makes available through a range of sources such as Jobcentres, Directgov, hospitals and doctors' surgeries to keep disabled people updated on its plans for implementation.** Clarity and certainty is essential to help reduce the apprehension felt by disabled people at this significant change and to reduce scaremongering or rumour.

Many of the disabled people we have consulted with called for the specific costs associated with having a disability to be mentioned within or recognised in addition to the criteria. These include everyday costs which are significantly higher for disabled people including accessible transport and utility bills. We recognise from the second draft criteria that the Government will not be significantly changing the assessment to factor in all costs which act as a barrier to disabled people's participation in society. Instead the 11 activities will be used as proxies for *some* of the additional costs of having a disability. It remains a concern that the opportunity to implement the social model of disability and reduce barriers for disabled people in the change from DLA to PIP will be missed. However we do accept the complexity of administering and maintaining fairness among claimants in a system based on the social model. Therefore in our response we have offered suggestions to improve the activities as proxies and ensure that they capture those with the greatest level of need.

Recommendations

Papworth Trust recommends that the second draft criteria for PIP be amended as follows:

- Prepared ingredients such as chopped vegetables should be considered to be an 'aid' under Activity 1
- Under Activity 2, people receiving nutrition through a therapeutic feeding source should be placed under descriptor E with 6 points.

- The definition of 'grooming' should be extended to include other grooming activities such as clipping nails and putting on make-up.
- Under Activity 5, incontinence pads be included as an 'aid' and that descriptor F be revised to: 'manage incontinence of either/both bladder and bowel' with 8 points awarded.
- The descriptors on dressing and undressing should include the need to frequently change clothes due to soiling. Our proposal for Activity 6 is demonstrated in Appendix 1.
- The communication activity should consider the impact of a memory impairment on understanding and expressing written and verbal communication.
- Under Activity 8, we would like to see a single situation used against which all claimants would be measured, preferably a situation where the claimant engages alone and face-to-face with a stranger.
- Making financial decisions needs to include assistance for making complex financial decisions for those people who have been institutionalised or do not manage their money for complex decisions.
- Papworth Trust is concerned about the likelihood of people with only a physical impairment qualifying for the enhanced rate of the mobility component. We suggest that those placed under descriptor D of Activity 11 should be awarded 12 points.
- The definition of 'safely' needs to be extended to include the severity of a risk, not just whether it is likely to occur.
- In the regulations we recommend that the definition of "bathe" be revised to: 'means to clean one's torso, face, hands and underarms *to a socially acceptable standard*'.

1. What are your views on the latest draft Daily Living activities?

Activity 1 – Preparing food and drink:

Papworth Trust would like to see descriptor B extended to capture the need to buy prepared foods, such as chopped or diced vegetables, meat, and other products which incur additional costs. A person may be able to prepare a meal without assistance but only because they have purchased easy to use or 'ready-made' ingredients. Purchasing prepared ingredients comes at a higher cost than unprepared ingredients, although it is less costly than employing someone to physically assist with cooking. Prepared ingredients should be considered as an 'aid' because they are used due to the difficulties associated with the individual's disability, for example reduced manual dexterity, rather than being a luxury, as they are for non-disabled people. We suggest that for the purposes of Activity 1, 'aid' should include the use of prepared ingredients.

Activity 2 – Taking nutrition:

Enteral and parenteral feeding cannot be used without support to manage the equipment. NICE guidelines state that 'All people in the community having parenteral [and enteral] nutrition should be supported by a co-ordinated multidisciplinary team, which includes input from specialist nutrition nurses, dieticians, GPs, pharmacists and district and/or homecare company nurses.'¹ Many will need assistance to manage the effects of therapeutic feeding

¹ NICE, 2006, 'Nutrition support in adults: oral nutrition support, enteral tube feeding and parenteral nutrition', p. 36: <http://www.nice.org.uk/nicemedia/live/10978/29979/29979.pdf>

including infection, pain, diarrhoea and the additional care associated with these problems. We recommend that descriptor C is removed and anyone receiving nutrition through therapeutic feeding be placed under descriptor E with 6 points. The definition of 'manage a therapeutic source' should include the implications of using these methods, such as regular infection, assistance from medical professionals, and from carers.

Activity 4 – Bathing and grooming:

In our response to the first draft criteria Papworth Trust called for the Activity 4 (Bathing and Grooming) to recognise achieving cleanliness in the bathing and grooming criterion, as simply being able to bathe unaided may not constitute cleanliness. We recommend that the definition of "bathe" be revised as 'means to clean one's torso, face, hands and underarms *to a socially accepted standard*'. That is, bathing to a standard which is necessary to take part in society where uncleanliness such as body odour or poor oral hygiene are detrimental, for example in employment.

Papworth Trust believes the definition of 'grooming' is very limited, and should be widened to include other grooming activities such as clipping nails, putting on make-up and similar activities which maintain a person's appearance and cleanliness.

Activity 5 – Managing toilet needs or incontinence:

Incontinence pads and Clos-o-Mat toilets should be classed as aids for the purposes of Activity 5. The use of a Clos-o-Mat toilet in particular may enable a person to manage their toilet needs independently, but obviously not without cost. The use of either of these aids indicates a prerequisite for management of toilet needs or incontinence and at additional cost.

Papworth Trust is unsure of the purpose of descriptor G, especially as the points awarded are the same for descriptor F which captures those with the highest level of need. Either a person can manage their incontinence with or without an aid, or they require intensive care and support in which another person intervenes in assisting and cleaning them. If descriptor G is kept then the guidance should include a clear explanation and example of the kind of situation which would satisfy that descriptor.

We are concerned that the weightings between descriptors E and F seem arbitrary. A person is likely to require just as much assistance to manage one function as they are both. We suggest that descriptor E be removed and descriptor F be revised to: 'manage incontinence of either/both bladder and bowel' with 8 points awarded.

Activity 6 – Dressing and undressing:

We believe the descriptors for Activity 6 need to include the frequency of dressing and undressing associated with a disability, for example the need to change clothes more often due to incontinence, soiling, food spillage (caused by difficulty eating), weeping sores, or prevention of infection. This should not include the clothing changes that any person would be expected to change for, such as playing sports, going out for dinner, etc. Amending this activity could make it a better proxy for the additional costs of more frequent changes of

clothes such as the additional costs of laundry and more regularly purchasing replacement clothing.

We seek clarification for the purpose of descriptor F. Again, this descriptor at least requires an explanation of how someone might satisfy this descriptor in the guidance, as either someone can dress themselves with or without an aid or they require assistance to get dressed. We recommend removing this descriptor and redistributing the points to descriptors D and E.

It is suggested that the descriptors be revised as demonstrated in Appendix 1 to take into account these costs.

Activity 7 - Communicating:

This criterion has a strong focus on hearing and sight impairments and is restricted to comprehending verbal and written information. We believe this ignores speech and language difficulties and the physical ability to write. Descriptor D could be amended by including the use of a scribe in the definition of 'access to written information'.

The criterion also needs to factor in the impact of having more than one communication difficulty. For example a person using a hearing aid and a communication device such as a light writer would currently receive only 2 points.

Descriptors C, E and F should be reworded to include retention of information, not just expressing and understanding information. A person with a brain injury may have no problem expressing or understanding information but could require an aid such as a recorder or assistance, such as a person to take notes, for lapses in memory or short term memory loss. We suggest that the descriptors could be revised to: 'Needs to use an aid or appliance to express, understand or retain verbal communication.'

Activity 8 – Engaging socially:

Papworth Trust would like to see a detailed explanation in the guidance of the hypothetical situation in which this criterion is being tested. In the same way that the Activity 11 looks at the ability to mobilise over a flat surface outdoors in scoring a claimant on the activity, there should be a similar standard situation for testing social engagement. There are obviously multiple forms of engaging with others socially, for example by telephone, over the internet, with friends, with strangers, in a group, alone, etc. As to 'engage socially' is defined in the regulations as being able to "understand body language" this assumes face-to-face engagement with a person, which should be made explicit. In the interests of fairness this needs to be set against one broad situation against which everyone can be measured and could be expected to do in their daily life. We recommend that the activity considers an individual's ability to engage socially face-to-face with a person unknown to them. This would capture those who are unable to confront this situation because of the overwhelming psychological distress it would cause and ensure they are awarded the highest points for the criterion.

It would be helpful to have clarification on what 'evidence' of previous incidences is required for descriptor D(i). Papworth Trust would like to see as broad a range as possible be

included, such as reports from schools and residential homes, support workers, carers and family members in addition to medical evidence.

Activity 9 – Making financial decisions:

Papworth Trust would like greater clarity around this criterion, particularly around the support required to make financial decisions.

We believe that the definition of ‘complex’ should be broad and more encompassing of the factors involved in making a decision, such as comparing products for value-for-money and affordability. An additional descriptor could be added for requiring assistance to make complex financial decisions. People who have been institutionalised or prevented from managing their finances may have no problem calculating costs and making purchases, but cannot tell if they are getting a good deal, whether they can afford to purchase it or if they could purchase a cheaper alternative. Looking for a good deal or needing to support to decide which offer is better value-for-money are the sort of circumstances where a person may require assistance. However we do not believe that requiring assistance should cover activities such as seeking professional financial advice.

Currently the criterion also excludes people who are not allowed to manage money for complex financial decisions, but can manage simple financial decisions, because they spend it inappropriately or are likely to be “ripped off” because of their vulnerability. This further indicates the need for a descriptor which covers ‘assistance’, or alternatively extending the definition of descriptor D to cover those people who do not manage their finances.

3. What are your views on the latest draft Mobility criteria?

Activity 10 – Planning and following a journey & Activity 11 – Moving around:

Papworth Trust is concerned that although descriptor D in Activity 11 captures people with strong mobility needs, it does not qualify them for the enhanced rate of the mobility component if they are only physically disabled (i.e. score no points under Activity 10), as opposed to having both physical and cognitive impairments. People with a physical impairment are reliant on Activity 11 as their only qualifying criterion for the mobility component, and therefore it is crucial that that this activity fully captures those people with significant mobility needs. It would be helpful to have more clarification on whether moving ‘up to 50 metres’ includes even shorter distances, such as 10 or 20 metres before the use of a wheelchair is required. To avoid confusion we suggest the removal of ‘up to’ in descriptors C, D and E.

People who use aids to walk short distances but rely on a wheelchair for anything longer will still be much less able to use public transport, and be more reliant on accessible taxis and the Motability scheme. Despite this they will not qualify for the enhanced rate of the mobility component, which is essential to passport to the Motability scheme. The difference in levels of support required between descriptors D and E is negligible. We therefore suggest that descriptor D is allocated 12 points.

We are unsure of the need to award 15 points in descriptors F and G when only 12 points are needed to receive the enhanced rate of mobility. Could the intention be that in order to passport to another benefit such as the Motability scheme a claimant must have received 15 points? Unless this is the intention then we suggest revising the points awarded to 12 in both F and G.

We believe descriptors B, C and D will effectively disallow a significant number of disabled people with moderate to severe physical impairments, and without cognitive or mental impairments, from receiving either the standard or enhanced rate. It is recommended that descriptor B is increased to 8 points to qualify people with a moderate mobility impairment for the standard mobility rate.

7. What are your views on the definitions of ‘safely’, ‘reliably’, ‘repeatedly’ and ‘in a timely manner’?

Papworth Trust would like to see the definitions for the above terms be included in the regulations as a general provision ensuring that they apply directly to all of the criteria, rather than being in the text of each criterion.

While we agree with the definition of ‘safely’ per se, risk is not well factored into this definition. Risk is defined as ‘the chance, high or low, that somebody could be harmed by ... hazards, together with an indication of how serious the harm could be.’²

Clearly, risk is not just the likelihood of an incident occurring, but also the degree to which health or life are endangered. The current consideration of risk as a factor in safety, described in the explanatory note, looks only at the likelihood that it may occur. This needs to be balanced with the severity of injury or death faced by significant risk, despite its likelihood being low. This is particularly relevant to Activities 1 and 4 where a person may not be able to complete the activity without supervision or assistance due to the small but significant risk of injury or death, such as drowning or receiving burns. This is well illustrated in Case Study 5 in the consultation document where Mary prefers to shower only when her husband is the house, presumably because although the risk she may have a fit is low, if it were to happen she may drown or be scalded by hot water, both significant risks to her life and health. Despite this Mary receives 0 points for Activity 4 because she can bathe and groom unaided. We recommend that the ability to complete the activity ‘without significant risk’, particularly when unassisted, be factored into Activities 1 and 4 in addition to ‘safely’, ‘in a timely fashion’, ‘reliably’ and ‘repeatedly’. Significant risk is defined as “those [risks] that are not trivial in nature and are capable of creating a real risk to health and safety which any reasonable person would appreciate and would take steps to guard against.”³ Furthermore, we disagree with the requirement that evidence must be provided to prove that an adverse event is likely to occur when the risk is substantial, again particularly under Activities 1 and 4.

² Health and Safety Executive, 2011, ‘*Five steps to risk assessment*’, p. 2:
<http://www.hse.gov.uk/pubns/indg163.pdf>

³ Health and Safety Executive, 2011, ‘*Frequently asked questions*’ [Accessed 23 April 2012]:
<http://www.hse.gov.uk/risk/faq.htm>

8. What are your views on the definitions in the regulations?

We believe that having a definition of ‘aid or appliance’ which excludes products used by non-disabled people is misguided. Products which may be a luxury or choice for non-disabled people can be expensive aids for disabled people who use them out of necessity. This includes products such as electric toothbrushes which could be used by people with reduced manual dexterity, and without which an individual would be unable to clean their teeth. We suggest that section (c) under the definition be revised to ‘*includes an aid or appliance ordinarily used by a person without a physical or mental condition which limits that person’s ability to carry out daily living or mobility activities, but for the claimant is a necessity used to lessen the impact of their condition in conducting these activities.*’

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

Under Regulation 7, paragraph 3, a claimant may be refused PIP if they fail to attend a face-to-face assessment without good reason when they have been given at least 7 days’ notice of the appointment. Papworth Trust strongly urges the Government to extend the minimum notice period to at least 28 days, and be mindful of the barriers faced by the people who seek to access this benefit. Problems associated with a 7 day notice period include:

- People with communication difficulties will need far longer than 7 days to arrange for support such as interpreters to attend an assessment with them.
- People who need information to be read or explained to them by another person because of their disability will require additional time.
- Advisory services and disabled people’s organisations will be overwhelmed and unable to assist anxious people seeking guidance or wanting an ‘expert’ to attend with them as an advocate.
- People who need time off work, to arrange childcare, or for a support worker, friend or family member to attend with them will face difficulty.
- People who have been admitted to hospital since making their application may not have access to their post and could be too unwell to make it to an assessment the following week.
- Scheduled therapies or treatments at hospitals, or with GPs or community nurses may conflict with the given appointment and be difficult to rearrange at short notice. It may also be necessary to receive the therapy or treatment at a specific time or on a specific day for management of a condition.

We are acutely aware that the guidance provided to assessors will be paramount to their interpretation of the criteria and how to apply them to claimants. We urge the Government to ensure that the guidance is not prescriptive about the symptoms, support required or barriers faced by people with specific conditions or impairments. Instead each individual’s disability should be treated as unique and symptoms or barriers should not be dismissed based on what is “expected” of a condition or impairment.

Finally, we would like to see a single document produced in accessible formats containing the final draft criteria and the general notes explaining the criteria (currently pages 44 - 47 in the explanatory note). This would greatly help claimants understand what they will be

assessed on and the kind of supporting evidence they will need to submit with their claim. It would also help to relieve some of the confusion and misinformation around the assessment.

In conclusion, Papworth Trust is keen to see the changes recommended throughout this response made to the second draft criteria to ensure that the assessment is fit for purpose and that the activities work successfully as proxies to the additional costs of having a disability.

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Appendix 1

Activity 6 – Dressing and undressing

| | | |
|---|---|---|
| A | Can dress and undress unaided. | 0 |
| | | |
| B | Needs to use an aid or appliance to dress or undress. | 2 |
| | | |
| C | Needs to use an aid or appliance to dress or undress more than three times a day other than for social reasons. | 3 |
| <i>For example: A person needs to change their clothing more often due to soiling caused by their disability, not for social reasons such as playing sport or attending a social event.</i> | | |
| D | Needs either – i. prompting to dress, undress or determine appropriate circumstances for remaining clothes; or ii. assistance or prompting to select appropriate clothing. | 2 |
| | | |
| E | Needs assistance to dress or undress lower body. | 4 |
| | | |
| F | Needs assistance to dress or undress lower body more than three times a day other than for social reasons. | 5 |
| | | |
| G | Needs assistance to dress or undress upper body. | 6 |
| | | |
| H | Needs assistance to dress or undress upper body more than three times a day other than for social reasons. | 8 |
| | | |