

PIP Second Consultation Feedback from Nottinghamshire Disabled People's Movement (Registered Charity No: 1076178)

Q1 - What are your views on the latest draft Daily Living activities?

In the explanatory note we set out revised proposals for the activities relating to entitlement to the Daily Living component (Activities 1-9). These include three new activities: Communicating, Engaging socially and Making Financial decisions. We would welcome your views on the activities. Are the changes and the new activities an improvement? Do you think we need to make any further changes?

NDPM response:

We think that the addition of the three new activities is a positive development. However, there are some major omissions that the activities do not cover which are essential for daily living. These include shopping and housework/domestic tasks.

Going shopping for food and drink is an essential pre-requisite for preparing food and cooking a meal. It is also necessary as part of daily living to go shopping for clothes, shoes and other essential items apart from food and drink. Someone with a visual impairment may need personal assistance with shopping in order to identify specific items to have them described etc, someone with a physical impairment may need assistance with taking items off shelves etc, someone with a learning difficulty may need assistance in deciding what to buy. This support would not be fully covered by the current Activity nine as it is just to do with making financial decisions, or by the mobility activities. Neither recognise/cover the need for personal assistance with these other aspects of shopping.

We believe that an Activity covering Shopping and another covering domestic tasks should be added to the list of activities.

Activity 1 Preparing and cooking food: in the notes it refers to cooking at above waist height. there is no reference to the preparation of food and the possible need to take food or cooking utensils from places e.g. fridges or storage spaces which are below waist height.

Re Activity 7 Communicating: this does not allow for any support needed during the process of communication. For example, someone may be able to talk on the phone, but need personal assistance from someone else if they cannot hold a phone.

The Daily Living activities do not cover essential activities such as shopping for items such as clothing, or for housework/cleaning a house. These were raised in the original feedback but do not seem to have been addressed in the revised criteria, although they are essential factors in independent daily living needs. Also raised in the consultation was the option to do leisure activities, this too is not covered in the revised Activities - are disabled people not expected to participate in leisure activities, which could lead to better physical and mental health and hence less need for support from national or local government?

We believe that the Activities should be extended to cover shopping (as mentioned above), domestic activities such as housework, washing clothes, etc. As was fed back in the initial consultation stage, leisure and community activities should also be included. See paragraph 3.7 of the draft Assessment Criteria Note.

Q2 - What are your views on the weightings and entitlement thresholds for the Daily Living activities?

In the explanatory note we set out proposals for the weightings of descriptors in the activities relating to entitlement to the Daily Living component (activities 1-9). In this document we have set out the entitlement thresholds for the benefit. How well do you think they work to distinguish between differing levels of ability in each activity? How well do you think they work to prioritise individuals on the basis of their overall need? Do you think we need to make any changes to weightings or thresholds?

NDPM response:

Activity 1 Preparing food and drink: no comment.

Activity 2 Taking nutrition:

See comments below in Activity 3 re the need for clear notes for assessors and which weighting should apply if this activity continues to cover both conveying food and conveying tablets to the mouth.

Activity 3 Managing therapy or monitoring a health condition:

In the 2nd draft of the criteria notes there is a reference to similar activities in Activities 2 and 3 in conveying food or tablets to the mouth:

"Ability to convey tablets to the mouth remains excluded as the same broad ability is assessed in activity 2, as part of ability to convey food to the mouth."

This is not the case for some disabled people. For example, someone with limited hand movement can convey food to the mouth by the use of an aid such as a splint with a fork (and depending on the food this may or may not need cutting up for them), however it would not be possible at all for that person to independently convey tablets to their mouth. For this reason, we believe that this needs to be addressed in the scoring for this activity; at present assistance with managing medication is weighted as 1 point. If it is decided that Activity 2 should continue to cover both conveying food and conveying tablets to the mouth, then notes for assessors need to be clear that the higher weighting is logged for Activity 2, i.e. that "Needs another person to convey food and drink to their mouth " should apply rather than "assistance to cut up food".

3B Managing medication: this should have equal weighting to managing therapy.

3C, D, E and F: Needing assistance with managing medication or therapy could be equally important in maintaining health /life saving.

It does not make sense to increase the number of points depending on how much time a day/week someone needs assistance with therapy (or medication). The support will always be needed (whether for half an hour a day or three hours a day etc and there should be no differentiation between these descriptors in terms of the weighting.

Activity 4 Bathing and grooming:

In 4.31 (criteria notes) there is an acknowledgement of the need to refer to washing all parts of the body - "Ability to wash the perineum after going to the toilet is still assessed within a different activity (Managing toilet needs or incontinence). It is no longer excluded

from this activity, as we recognise that it is part of normal bathing;...". However, the notes for the activity only say: "Bathing is the ability to clean one's torso, face, hands and underarms. ". It would be much clearer if more detail was given for 'torso' i.e. to include a reference to legs, feet, perineum etc. For some people, being able to wash the perineum may be relevant for Activity 4 but not in Activity 5 or vice versa. So there is a need for clear information in both of the notes for these activities.

4G and H: why is there a difference in weighting between needing assistance to bathe and cannot bathe at all,? If someone needs assistance, they need assistance. We recommend that the weighting should be changed to 8 points for both.

Activity 5: managing toilet and incontinence:

See above re the need for clarity and clear notes re the ability to clean the perineum.

5E and F: why is there a differentiation between needing assistance to manage incontinence of either bowel or bladder, or both? Assistance is needed for both 5E and 5F and we believe there should be no discrimination between the two and they should have equal weighting.

Activity 6 Dressing and undressing:

6D and E: Why is there a difference between dressing the lower or upper part of the body? All parts are equally necessary and important and both need personal assistance. We believe these should be equally weighted and higher than currently to address the 'large' gap between E and F.

Activity 7 Communicating: no comment.

Activity 8: Engaging socially: no comment.

Activity 9 Financial decisions: no comment.

Q3 - What are your views on the latest draft Mobility activities?

In the explanatory note we set out revised proposals for the activities relating to entitlement to the Mobility component (activities 10-11). Are the changes an improvement? Do you think we need to make any further changes?

NDPM response:

In the definition of support dogs, this only refers to people with a sensory impairment. There needs to be a recognition that assistance dogs may work with people with other impairments and may be relevant to mobility activities too e.g. an assistance dog may help a manual wheelchair user to go uphill.

There is no mention of the use of long canes anywhere in the regulations or assessment document. These need to be included alongside the use of support dogs.

Q4 - What are your views on the weightings and entitlement thresholds for the Mobility activities?

In the explanatory note we set out proposals for the weightings of descriptors in the activities relating to entitlement to the Mobility component (activities 10-11). In this document we have set out the entitlement thresholds for the benefit. How well do you think they work to distinguish between differing levels of ability in each activity? How well do you think they work to prioritise individuals on the basis of their overall need? Do you think we need to make any changes to weightings or thresholds?

NDPM response:

Activity 10 Planning and following a journey:

10D and E: as mentioned in the response to Q3, these should include a reference to the use of a long cane. The definition of a support dog should be extended to assistance dogs who may work with people with mobility difficulties, for example a manual wheelchair user may use an assistance dog to help the wheelchair user go uphill.

Activity 11: Moving around:

11B and C: why differentiate between people who can walk up to 200m and those who can only walk up to 50m? When going shopping for example, there would still be the need to walk more than 200m in order to get both to and from a shop and walk around it. We recommend that the score for B and C should both be 8.

11C and D: why differentiate between those who can walk up to 50m unaided and those who can walk the same distance but need an aid for example a walking stick to do so? Both situations have an equal effect on ability to move around and we believe should have equal weighting. We believe that the weightings for both descriptors C and D should be raised to ensure that anyone who needs to use a wheelchair would fall within the higher rate of the mobility component of PIP.

11E and F: should there be any change in the weightings, we believe that meeting these descriptors should remain as qualifying for the higher rate of the mobility component of PIP.

In addition, in the criteria notes 4.35 there is a reference to costs:

"For the Mobility component, the descriptor weightings for activity 11 (Moving around) reflect the extra costs associated with mobility aids, ensuring that individuals who require aids and appliances to move very short distances receive some priority in the weightings, while individuals who use a wheelchair would receive greater priority."

There does not seem to be any acknowledgement of the costs associated with buying and maintaining mobility aids such as long canes or talking navigation aids, or with the cost of looking after a guide dog.

Q5 - What are your views on how the regulations work regarding benefit entitlement?

Draft Regulations 1 to 4 set out how the assessment will work to prioritise individuals and determine entitlement to the benefit. How well do you think the draft regulations achieve the intent of the assessment set out in the explanatory note? Do we need to make any changes?

NDPM response:

In Regulation 4(c)(iii) - We believe that the process in the draft document could discriminate against some people, depending on what type of support they need and how often they need it. We think a fairer method when someone has an issue which is less than 50% of the time, whichever is the higher score for support needed between 30% and 50% of the time, the higher score should be used.

Re Regulation 4(d)(i) and (ii), we believe this needs revising as it does not cover temporary or intermittent situations. For example, if someone with a prosthesis cannot wear it all the time, due to skin conditions, level of good design/fitting etc, or if someone with a visual impairment had problems with their wrist and could not use a cane or guide dog.

Q6 - What are your views on how we are dealing with fluctuating conditions?

Regulation 4(4)(c) of the draft regulations and paragraphs 7.13 to 7.15 of the explanatory note set out how we are proposing to assign descriptors to people who have fluctuating conditions. These are that:

- Scoring descriptors will apply to individuals where their impairment(s) affects their ability to complete an activity on more than 50 per cent of days in a 12 month period.
- If one descriptor in an activity applies on more than 50 per cent of the days in the period - i.e. the activity cannot be completed in the way described on more than 50 per cent of days - then that descriptor should be chosen.
- If more than one descriptor in an activity applies on more than 50 per cent of the days in the period, then the descriptor chosen should be the one which applies for the greatest proportion of the time.
- Where one single descriptor in an activity is not satisfied on more than 50 per cent of days, but a number of different descriptors in that activity together are satisfied on more than 50 per cent of days - for example, descriptor 'B' is satisfied on 40 per cent of days and descriptor 'C' on 30 per cent of different days - the descriptor satisfied for the highest proportion of the time should be selected.

What are your views on this approach and how this is set out in the regulations?

NDPM response:

As previously stated in our response to Question 5, we believe that the process in the draft document could discriminate against some people, depending on what type of support they need and how often they need it. We think a fairer method when someone has an issue which is less than 50% of the time, whichever is the higher score for support needed between 30% and 50% of the time, the higher score should be used.

Q7 - What are your views on the definitions of 'safely', 'timely', 'repeatedly' and 'in a timely' manner?

In the assessment an individual must be able to complete an activity descriptor reliably, repeatedly, safely and in a timely manner. Otherwise they should be considered unable to

complete the activity described at that level. In paragraph 7.4 of the explanatory note we set out draft definitions for these as follows:

- Reliably means to a reasonable standard.

NDPM response: Who will determine what is a 'reasonable standard'?

- In a timely fashion means in less than twice the time it would take for an individual without any impairment.

NDPM response: How would the time someone without an impairment would take be measured/calculated?

- Repeatedly means completed as often during the day as the individual activity requires. Consideration needs to be given to the cumulative effects of symptoms such as pain and fatigue - i.e. whether completing the activity adversely affects the individual's ability to subsequently complete other activities.

NDPM response: We welcome this definition.

- Safely means 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.

What are your views on these? Some organisations have suggested that these terms should be included within the regulations. Do you agree? If so, do you have views on how we should do so - for example, as a general provision or referring to them in the detail of activity descriptors?

NDPM response: Yes, we do feel they should be included with the regulations. They should also be in a general section before the activities. They need to be easily accessible and available and easily found by whoever is doing an assessment.

Q8 - What are your views on the definitions in the regulations?

The draft regulations contain a number of definitions in Regulation 1 (Interpretation) and Schedule 1. Do we need to make changes to any of these?

NDPM response:

We feel some definitions need amending.

- Aids need to include the use of long canes.

- Bathing needs to include and be more specific re the torso i.e. the whole body including the lower part of the body, i.e. feet, legs etc.

- Cooking ("cook" means heat food at or above waist height") - this needs amending to include activity below waist height. Cooking food involves preparing it and this may involve taking crockery out of lower cupboards, taking food out of a floor standing fridge, or putting food in an oven which could also be below waist height.

- Support dogs need to include assistance dogs which may assist with making a journey (e.g. helping a manual wheelchair user go uphill), but could also assist someone at home for example fetching or carrying items, assistance with pulling on clothes etc.

- Therapy: why is only therapy at home included in this definition? Long term therapy may need to take place somewhere outside the home e.g. at a local gym.

Q9 - Do you have any other comments on the draft regulations?

Regulations 5 to 10 of the draft regulations relate to elements of the assessment process for Personal Independence Payment, around the requirement to provide information and attend face-to-face consultations, the consequences of failing to meet these requirements and when individuals might have good reason for not meeting these. Do you have any comments on these regulations?

NDPM response:

Regulation 5:

In "(1) Information required for determining limited or severely limited ability..." (a) and (b): Rather than an applicant just providing information that has been requested, it should be possible for someone to use/provide information which they feel is relevant and should be taken into account.

In (2) re "information shall be provided to the Secretary of State within one month...": the period of one month needs to be extended to a minimum of at least six weeks. It may take someone longer than a month to obtain the requested information, for example if a doctor is not available. It may also take someone with a visual impairment or learning difficulty some time initially to have an inaccessible document to be read and explained to them. Contact details such as a phone number or email address should be provided with all correspondence in order for someone to be able to easily give an update on any delays. How are applicants expected to cover the cost of getting hold of/providing information, for example doctors often charge for providing medical records or letters for medical evidence?

Regulation 6 Failure to provide information... : how is 'good reason' to be determined?

Regulation 7 Claimant may be called for a consultation... :

In (3): notice of at least seven days is not long enough. there are a wide range of reasons as to why seven days is not long enough for many disabled people. For example, it may not allow for someone to have the information read to them, to enable support needs to be set up, if someone needs to arrange for an interpreter or support worker to accompany them, to arrange accessible transport etc. What if someone was on holiday? The period of notice should be four weeks.

There is no mention in this regulation of the option for someone to be accompanied by an advocate or other support at a meeting.

Regulation 8 Matters to be taken into account...: In (B), the reference to the 'nature of any disability' needs to be extended to cover linked issues, such as being able to sort out necessary access/support needs e.g. the availability of an interpreter or guide.

Regulation 9 Re-determination of ability to carry out activities: what would be the grounds for a review/re-determination?

We note that there is no provision in this or other regulations for an appeal against a decision and believe that another regulation should be added to cover an appeal process.