

PIP Second Draft Consultation
Feedback from National Federation of the Blind Nottingham Branch

29th April '12

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?

Our 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, or locating and taking items off shelves etc. This type of 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 think 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;
- The reference to fresh food includes tinned food, but should also include frozen food;
- Someone with a visual impairment (VI) may need to get help from someone to read tins, assistance with reading instructions on packaging etc;
- People should not be expected to live on microwave cooking.

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 find a phone or dial.

Activity 9:

- This does not take into account assistance needed with banking etc due to systems which are not accessible to people with a visual impairment e.g. Internet banking and ATMs;
- There is a need for descriptors to cover these type of issues, someone with VI may be able to make complicated financial decisions but may need help with doing so due to inaccessible systems, i.e. it is not about making a decision but having accessible information on which to make a decision.

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 feel 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.

In addition, the examples given in the case studies do not seem to reflect how they should have been scored/weighted from the descriptors.

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?

Our response:

Activity 2 Taking nutrition:

- 2(c): We feel that needing to use a therapeutic source to take nutrition should be a higher score than 2 i.e. 4;
- Why is the top score in this section 10? This is higher than the top score in Activity 1 and a support worker would be needed in both the higher scoring sections of Activity 1 and Activity 2. We think the highest scores of activities 1 and 2 should be the same i.e. 10.

Activity 3 Managing therapy or monitoring a health condition:

- If someone needs to use an aid such as a medicine box, this should score at least 2;
- 3(b) re the need for supervision re monitoring or prompting, this should be a higher score e.g. 4;
- 3(c) should be combined with 3(b) and still be 4;
- Why differentiate between 3(b) to 3(f), all are important and all need assistance from someone. It does not make sense to increase the number of points depending on how much time a day/week someone needs assistance
- We suggest that 3(b,) (c) (d), (e) and (f) are combined and all at the same weighting.

Activity 4 Bathing and grooming:

- Why does the information about the descriptor not include legs and feet?
- People with a VI may need assistance with identifying items, reading labels e.g. shampoo, including 4(d) if someone cannot read braille;
- Supervision or prompting to bathe only scores 2; we feel it should be higher.
- 4(g) and (h): why is there a difference in weighting between needing assistance to bathe and cannot bathe at all? Someone would need assistance in both cases. We think that the weighting should be changed to 8 points for both.

Activity 5: managing toilet and incontinence:

- Re 5(d), if someone has a VI they may need assistance to find a toilet and this should score higher e.g. 4;

- 5(e) and 5(f): Why should the scores for these be different? Assistance is needed for both 5(e) and 5(f) and there should be the same score for both.

Activity 6 Dressing and undressing:

- In the description for this activity it does not refer to people with a VI needing assistance re e.g. to be told they have a dirty mark on a shirt;
- 6(d) and (e) should have the same score, dressing the lower or upper body are equally important and both need personal assistance. We think these should be equally weighted and higher than currently to address the 'large' gap between E and F.

Activity 7 Communicating:

- 7(e) and (f): Notes for assessors should be clear that both would apply for someone using British Sign Language (BSL) and hence they should be scored at the higher weighting.

Activity 8: Engaging socially:

- What is missing is that some people with a VI do need support re engaging socially due to issues such as not understanding body language, due to not being able to see it. A definition of someone providing social support should be included for visual impairment;
- Re 8(b) and (c): separating prompting and assistance does not seem to be logical, don't these overlap and both need personal assistance?

Activity 9 Financial decisions:

- 9(d): We feel the weighting should be higher i.e. 8.

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?

Our 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?

Our response:

Activity 10 Planning and following a journey:

- What does 'capable' of using public transport or making a journey mean?

This needs some clarification;

- 10(d) and (e): as mentioned in the response to Q3, these should include a reference to the use of a long cane;
- People using guide canes should score lower than those using long canes;
- It should be noted that sometimes, given environmental conditions (e.g. snow), people with vi will need assistance for familiar journeys;
- If assistance is needed with making familiar or unfamiliar journeys, these should both be a higher score i.e. 15.

Activity 11: Moving around:

- 11(b) 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.
- The score for (b) and (c) should both be 8;
- *11(c) 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 should have equal weighting;

- We think 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.

- 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?

Our 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 think 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?

Our 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.

Our 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.

Our 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.

Our 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?

Our 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?

Our response:

We feel some definitions need amending.

- Aids need to include the use of long canes and other mobility aids such as guide canes, navigation aids.

- 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?

Our 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 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 is 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.

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