

Consultation questions

Response from People First (Scotland).

People First (Scotland) is the national self advocacy organisation of people with learning difficulties in Scotland. The organisation is run by people with learning difficulties and has around 100 local groups throughout Scotland. People First representatives sit on many national policy fora with the Scottish Government and other national organisations and scrutiny bodies.

1 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?

We think the changes are an improvement. However we think these further changes are needed to fully recognise the needs of people with learning difficulties:

Activity 3 – Managing therapy or monitoring a health condition

Needing support to attend healthcare appointments also needs to be included in this section. This support is crucial for many people with learning difficulties who may lack the confidence to attend appointments on their own, explain their symptoms or fully understand what they are being told.

Activity 4 – Bathing and grooming

Shaving needs to be included here.

We do not understand why some areas of the body are specified and not others. What about feet, legs, arms? Depending on the nature of someone's impairment they may need support to wash certain parts of the body but not others.

Activity 6 – Dressing and undressing

Why are only slip-on shoes included? Why should our choice be limited to these if we like to wear shoes with laces?

Activity 7 – Communicating

We think that D needs to be split into two categories:

- a) needs support to access complex written information including needing information in an alternative format (e.g braille, easy read)
- b) needs support to access basic written information

Many people with learning difficulties need support to access written information. Basic written information should include every-day information such as letters, bills, information about services etc. Complex written information should include information such as legal documents, policy statements etc.

Accessing information and *understanding* both verbal and written information are both important. This needs to include support to think through what the information means and how it may apply to them. Many people with learning difficulties can understand the actual words but not what they mean or how to apply the information to their lives.

G – We do not know of anyone who cannot communicate *at all*. Including this category gives an impression that some people cannot communicate anything. This would probably only be true of someone who was in a coma or on a life support machine. We think it would be better to say *needs intensive support to communicate*.

Activity 8 – Engaging socially

We think there needs to be another category here of people who need support to establish new social connections.

Activity 9 – Making financial decisions

We think there needs to be additional categories here of people who:

- I) Need supervision or assistance to make simple financial decisions
- II) Need supervision or assistance to make complex financial decisions

Needing supervision or assistance is very different to needing 'prompting' which suggests a much lower level of support needed. Many people with learning difficulties require considerable support to manage their money. This does not mean that they cannot make any financial decisions, but that they need the right kind of ongoing support that breaks things down sufficiently and that takes things at their own pace.

There is nothing in these activities about managing your own household – we think this needs to be added. This would include things like housework, shopping, washing clothes, ironing etc

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?

We think that some of the weightings need to be changed.

Daily living activities:

Activity 1

D - we think this should be four points

E and F – we think we should both be six points.

For D, E and F a person would need someone with them. This therefore incurs additional expense.

Activity 3

B – we think this should be at least two points as the consequences of not doing this could be very serious.

Activity 4

E and F – we think these should both be four points. Again they would require the additional expense of having someone with you or special equipment.

G – we think this should be six points as a person would need someone with them.

H – we think this should be 10 points as a person would require such a high level of support.

Activity 6

We do not understand why D and E score different points. We think both should be four points. We do not think it takes longer or requires any more personal care or incurs any additional expense to dress or undress the upper body than to dress or undress the lower body.

Activity 7

C – we think this should be four points as communication aids and appliances can be expensive and need updating.

As stated above we think that the category about written information (D) should be split into two sections.

a) needs support to access complex written information including needing information in an alternative format (e.g braille, easy read) should be four points.

b) needs support to access basic written information should be eight points.

If someone is unable to access even basic written information this can lead to serious consequences such as getting into arrears with rent or mortgage payments and ultimately losing your housing.

Activity 8

As stated above we think there needs to be another category here of people who need support to establish new social connections, and that this should attract four points.

C – we think this should be six points as somebody would need support with them all the time in social situations.

D – we think this should be 10 points as it would require intensive support.

Activity 9

As stated above we think there needs to be additional categories here of people who:

- I) Need supervision or assistance to make simple financial decisions – for 8 points
- II) Need supervision or assistance to make complex financial decisions - for 6 points

The potential consequences of somebody not getting this support are very serious.

D – we think this should be 10 points as it would require intensive support.

• **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?

Activity 10

We think there needs to be an additional category of:

- needs assistance to plan a journey to an unfamiliar destination – for 6 points

• **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?

See answer to Q 3 above.

• **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?

• **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:

- 1 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.
- 2 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.
- 3 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.
- 4 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.
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What are your views on this approach and how this is set out in the regulations?

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• **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:

- 1 **Reliably** means to a reasonable standard.
- 2 **In a timely fashion** means in less than twice the time it would take for an individual without any impairment.
- 3 **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.
- 4 **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.

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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?

• **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?

‘bathe’ – this also needs to include washing feet, legs and arms.

‘communicate’ – this needs to include conveying, accessing understanding and applying information. (See comments above)

‘dress and undress’ – this should include putting off and taking off socks and shoes (it should not be limited to slip-on shoes)

‘groom’ – this should also include shaving.

• **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?

We are concerned that regulation 7 (claimant may be called for a consultation to determine whether the claimant has limited or severely limited ability to carry out activities) does not give the claimant any entitlement to support to participate in the consultation either in person or by telephone. Many people with learning difficulties would struggle to attend such a meeting or manage such a phone call without support. 7 (3) needs to specify that the written notice must have been given in an accessible format which the claimant could understand.

5.5 Other comments on the second draft criteria – in particular on the changes made in the November 2011 version, the proposed weightings and the entitlement thresholds – are welcome. At this point in the development process we do not envisage making significant changes to the broad principles or scope of the assessment – i.e. to incorporate social and environmental factors. We are therefore not seeking comments on these aspects of the second draft criteria. We are also not seeking views at this stage on Regulations 11 to 13 of the draft regulations relating to the required period conditions. These will be subject to separate consultation at a later point.