

## PIP Public Consultation Response

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**“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?”**

Response: bearing in mind that we are looking at people with learning disabilities our answers will come from that perspective. We understand that several charities were consulted including Royal Mencap and the response from them was too difficult to implement within the new system. However, we believe that by adding filter questions preferably at the beginning of the process those qualifying people with learning disabilities can be ruled into the process very simply. For example, those who qualify under the Mental Capacity Act 2007 should automatically qualify for both higher rates, as clearly they will be unable to look after themselves without support and would be unable to fill in this form and would need someone to do this for them. In addition they clearly would not be able to organise an journey as they would need to be taken everywhere with support and although they may be able to walk, they would not be able to do this safely without support certainly would have difficulty using public transport. (with regard to mobility component this is equally true for many people on the Autistic Spectrum who may struggle with crowds, those with Challenging Behaviours and those who are very vulnerable and subject to abuse because they are slow and do not react as quickly as Joe Public thinks they should).

You should establish if the person filling in the form can read or/and understand the form. We know some people with learning disabilities may be able to read some words, but do not understand context ergo it is just words. This is a simple set of questions. Some people with moderate learning disabilities, who may only require a little help, may still need support to fill out forms to ensure they are not being excluded from the system.

It is important to consider pain, tiredness and behaviours when considering how people can complete these tasks. The concept of Repeatedly, Safely, Reliably and in a Timely Fashion, not only applies to physical difficulty but especially to those with mental capacity issues. There are many people with learning disabilities who may always need reminding what to do and may never successfully remember how to do the task in say an hour let alone the next day. Others may take a long period of time to learn tasks and others may pick these skills up more quickly. Filtering those skills before the main body of the questionnaire could be very helpful.

Also within the descriptors

Activity 2 there is nothing that covers temperature of the food, would you know it was too hot? Would you need help to stop eating it too quickly? This could be a danger and should be somewhere in the D category. Prompting people to eat is as important as preventing people eating too quickly and making sure the food is a safe temperature and size. Do you need special food preparation like pureed or soft food and what if you can't chew? Under health conditions where is challenging behaviours and management techniques?

Activity 3 it is disappointing this does not include over the counter medication. i.e. someone with severe LD who may need ibuprofen for period pain and may need liquid form all accessible at the chemist, still would need someone to know they were in pain, know they needed medicine, know they needed to have it administered and administer. My daughter is in this position and was advised to medicate in this way by a doctor, but it is not prescribed mainly because it is cheaper over the counter. It would be expensive and financial incompetent for health professionals to add to the medications bill. It does not take away the necessity for the use of over the counter medication. Then you are saying if the GP prescribes ibuprofen its okay but if you still need it and it's over the

counter it's not okay. That is neither fair nor prudent.

Activity 4 Bathing is the ability to clean ones torso, face, hands and underarms? Really Bathing should be your body, this is really ridiculous and should be changed as a matter of urgency. People need their lower halves and legs and feet washing and is crucial if you are incontinent to say nothing of the upkeep of skin, problems with leg ulcers, bed sores and so forth, this is making problems for those who already have illness and disability. Additionally if a carer told social services they would only consider these parameters for bathing you would rightly be accused of neglect you need to sort your standards out. Would anyone wish to work in your office if bathing ignores the lower half! I think not. You do not consider hands and feet – care of nails, Hard skin etc

Activity 6 do you need help to keep your clothes on? We know of members who would need help to ensure they remained clothed appropriately at all times. In addition although they may be able to strip off at inappropriate moments, it doesn't mean they can dress or undress accordingly because of their LD and behaviours.

Activity 7 – Communication is a hearing aid special equipment? We are surprised there is not a category between F and G. What about people who use a little Makaton? PECS? Objects of Reference? They may have very little communication but when filling in the form it may be difficult to say they have no communication and as those people do not fall into F ergo they are G. A little more thought please it is demeaning for all the effort that has been put in to aid with the smallest amount of communication.

Activity 8 Engaging Socially is important for those with LD. If you need help to engage Socially only counts if help comes from someone with special training. This should include those who know you well and parents and relatives. I know this from personal experience. I don't have special training just 27 years of caring. You must not exclude those with the greatest knowledge, which does not come with an NVQ! This must be modified.

Activity 9 We are aware there are capacity issues however some people may need actual help to go to the bank, building society and handle transactions as well as pay their bills. There does not appear to be an upper rate category for this.  
What about help with any other kind of form filling? Official returns, 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?

**Response**

**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?**

## **Response**

**Activity 10 must include those who cannot use public transport at all or very easily. This would be those with challenging behaviours who may be a danger to themselves or others, who may be very distressed in crowds and those very vulnerable people for whom travelling on public transport would be very difficult and leave them open to abuse i.e. because they are very slow, have difficulty understanding or become frightened. Consideration for those who cannot go anywhere without 1-1 should also score highly, especially if this is because of no awareness of danger, road traffic and inability to get from a-b alone etc**

**Anyone who needs 2-1 support to go out should qualify automatically for enhanced rate**

**Activity 11 does this mean 25m each way? Etc. It's no good going 50m if you can't get back surely**

**What is your status if you need help moving around**

## **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?**

**Response:**

**“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?”**

**Response: within our experience hardly anyone with a learning disability would be able to read and understand these regulations and therefore must have access to advocacy in order to ensure that claimants are getting the right amount of benefit to which they are entitled. This is imperative.**

**“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?”**

**Response:**

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

**Response: we agree these terms should be included within the regulations, for people with learning disabilities these are key factors in helping to assess the level of need. Care must be taken to ensure advocacy is available for those with learning disabilities to ensure that they understand as much as possible the process and that information can be communicated to the assessor.**

**We would like to see something which takes account of the applicants understanding. If they don’t understand or have capacity to understand then they should qualify.**



**“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?”**

**Response: we have commented throughout the document. Would reiterate that people with learning disabilities will need advocacy. The majority will not be able to understand these documents and will need help.**

**“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?”**

**Response: and again people with learning disabilities will require advocates to ensure the correct participation in this exercise. I did not see the offer of a home visit which could be crucial. For many the interview could be done on the telephone but would very likely have to be with an advocate, relative or representative. If the government accepts that communication is a high scoring element that would apply to many of our members. We would not like to see our members forced to attend offices which may lead to stress, challenging behaviours and outbursts, a great number of difficulties for those on the Autistic Spectrum and any other number of problems which could be avoided. The idea is to help those in need and flexibility within the system to accommodate this would be appreciated.**

## Other Comments

“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.”

Response: we do have a concern as to what would be considered a care home. Would 3-4 people sharing a property be in danger of losing benefit? Those in a large sheltered facility? It would be very helpful to have clear cut guidelines about what situations would be affected by this. Those currently in a care home situation with learning disabilities, but who integrate regularly into the local community with the support of their benefit, would basically become home bound if it were removed. We would consider this to be a totally unsuitable outcome and would request that the consideration of The Human Rights Act be very important to ensure that those people would have a continuation of the support to have a life. This would also be supported by Valuing People and Valuing People Now.

We would add that in terms of qualification – people are born with learning disabilities and will have them for life. They are amongst the most vulnerable citizens and every effort must be made to help them as much as possible to live as good a life as they are able to achieve.

As a suggestion, there are many local charities with facilities which people with learning disabilities would be familiar and comfortable. Perhaps assessment surgeries could take place regularly within these venues. This may well help with providing some kind of support and advocacy and facilitate a good outcome for the claimant and the assessor.