

Re: Personal Independence Payment Consultation

Response from Southampton Learning Disability (LD) Partnership Board

23rd April 2012

The following comments have been collated by the members of the Partnership Board, the local self reference group to the Board and the subgroup of Family Carers. They were endorsed, discussed and added to at the LD Partnership Board meeting on 23rd April

1. What do you think of the government's latest idea about the daily living activities?

There is a question re medication and ability to self-administer. In some case, if the person did take medication, they would need full support to take it. However they do not normally need medication and so will not score any points for this question. This seemed confusing

The distinction between Supervision, Prompting, and Assistance seemed helpful in deciding the level of support required and so the weighting to give for the support. The difference between Standard and Enhanced payments simplifies the old system which has 3 levels and could be fairer because there is less of an overlap between the bands and hopefully this will prevent people with broadly similar needs getting slightly different payments.

If someone gets a direct payment to help them with their daily activities, perhaps to take their medication we were unclear how this would effect the amount of either their care package or ability to claim for PIP.

2. What do you think of the Government's ideas about the points allowed for daily living activities and the points you need to get this component?

We wanted to be sure that there wasn't a slant towards people with physical problems, and no mention of assessment specific to people with a LD There were general concerns about the qualifying criteria.

We wondered if there are enough questions to ascertain Mental Health & LD needs to gain sufficient points in comparison to physical disability

3. What do you think of the government's latest ideas about the mobility activities?

There are only 2 points. Planning a journey and following the plan or moving around. For people with LD they may be able to plan but if something unexpected happens they will then not be able to carry on. It seems to be either you can or cannot do the journey. Or another example might be to have extra questions re a person's special awareness (e.g. a situation where there are restrictions when walking on a pavement)

It seems there was a narrow bracket of points for the 2 levels of benefit

4. What do you think about the government's ideas about the points allowed for mobility activities and the points you need to get this component?

We thought that if the questions asked for each bit included thinking about all aspects of the journey and not just the physical things then it was ok.

However there were concerns about the qualifications for this component.

There does not seem to be an acknowledgement that a carer/supporter is also an aid for a person just as much as any other walking aid.

We were not sure it asked clearly what the impact of not having support to go out would mean.

5. What do you think of what the regulations say about deciding who can get the payment?

We were worried about where the half million who will not get the benefit in the future would come from.

We were not sure what would happen for people who have currently got DLA without reassessment. We see that the regulations include eligibility criteria which are unlikely to affect applicants who are in receipt of "indefinite" payments under the current arrangements except if there is some change in the status of the disability over time which is unlikely in claimants who have congenital conditions. However there may be a requirement for a face to face assessment unless there are factors which make that inappropriate

6. What do you think about the government's ideas for dealing with health conditions that are sometimes a little better and sometimes a little worse?

We think it is really important that the people making the decisions understand about the needs of people with LD, and how to ask the questions to get a real response. For example someone might be asked if they go

upstairs. A wheelchair user with a learning disability asked this said yes as they had in the past.

Medically qualified people should carry out assessments not just health workers

For people with multiple needs how will they select which relevant qualified person to do assessment

7. What do you think about the government's ideas about the meanings of the following words – safely, reliably, repeatedly and in a timely fashion?

We thought that having the explanations was helpful to understand what was meant

It seems important that questions specify whether this is with or without a support worker – lots of people will say yes they can do this as the support is given in a subtle way to maximize a person's esteem.

8. What do you think about the way the regulations show the meanings of words?

We thought this was good

9. Do you want to say anything else about the draft regulations?

- There is a suggestion that individuals can bring people to support them, however it is not clear how this might be paid for. For example if they want an advocate to come this is not something current services are funded to provide. If there are appeals about decisions how will advocacy be funded for people?
- We think it is very important to have a lot of good notes to explain the process as if someone with a learning disability is going to the assessment alone they will need help to understand the questions
- People with learning disability were worried that as their disability cannot be seen they might be discriminated against. It is easier if someone is in a wheelchair
- We felt that there are a lot of changes and new names for things and that with personal budgets for those who have a care package and then PIP it might lead to confusion
- How will the assessment change for people with LD, i.e. will it be longer?
- If someone loses their entitlement to benefit will they also lose other benefits like a bus pass. This would make it even harder for people
- We thought it was good change from the 42 page document that people have to fill in at the moment and that this was clearer