

## **Bristol and S.Glos LINKs Self Directed Support Working Task Group**

### **Personal Independence Payment**

#### **Joint Response to the Consultation March 2012**

#### **Consultation questions**

**Question 1** – What do you think of the government's latest ideas about the daily living activities?

- It is better than the RAS but needs more work as it is too complicated.
- The priorities are in the wrong order.
- It is flawed, there is nowhere near enough thought on complexity.
- It is trying to standardise something that cannot be standardised, people's priorities are different.
- Very general words are used and have to be interpreted.
- The points system is very confusing.
- Is this reverting to the medical model?
- The PIP needs a lot more work and implementing gradually.
- Will the assessment take place over 24 hours?
- What happens when you are 64?
- It takes a very simplistic view; it needs detailed information not a tick box exercise.
- It will put disabled back into extreme poverty.
- The threshold of disability will be raised – some 500,000 people will not receive payment.
- Day centre care is to be paid for from an individual's PIP.
- Who will look after the PIP payments for e.g. head injury victims?
- Not all disabled people have been consulted.
- A draft copy of the assessment should be sent to the person for clarification/agreement before it is signed off.

- Assessing people with lifelong disabilities is a waste of time and money.
- Assessing people with challenging behaviour is difficult.

#### Additional points from the RNIB

- The PIP assessment will score people on their ability to travel by themselves to familiar and unfamiliar locations. We are concerned that people may lose their mobility allowance when they are reassessed. We want the government to acknowledge that blind and partially sighted people can be put at risk by unexpected obstacles even on familiar routes and regularly have to use taxis to travel safely.
- The 'Moving around' PIP criteria has been designed so it relates to an individual's physical ability to move around. This is despite cross-party recognition of the impact of sight loss in this activity just two years ago. Unexpected barriers and obstructions can present a huge risk of trips and falls to blind and partially sighted people and negotiating an unfamiliar space can pose a huge challenge.

Does the government need to make more changes to this? **Yes**

**Question 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?

- Assessment should take place over 24 hours to view the person's disability.
- It is replacing the DLA and is a lot narrower and more prescriptive.
- Toileting needs a higher points scale.
- It does not distinguish enough between levels of disability.
- The criteria do not include definitions – it requires the assessor to know all about complex needs.
- It relies on the assessor's role – there is no internal appeal system but there needs to be.

- It needs consistency of assessment.
- Will there still be self assessment? The regulations document (page 6; item 7) states that it could be carried out by telephone.
- There is concern over the assessment of people with memory problems/brain injuries who may not be able to cope with this.
- The points system is arbitrary.
- The interpretation of the previous consultation – what is reasonable?
- Complex needs are not considered. No one question fits all disabilities; the assessor will need expertise in a full range of impairments.
- People who cannot cope with paperwork will miss out.
- Will assessors be contracted and will a professional person be with the person to be assessed?
- A draft copy of the assessment should be sent to the person for clarification/agreement before it is signed off.
- Assessing people with lifelong disabilities is a waste of time and money.
- Assessing people with challenging behaviour is difficult.

#### Additional points from the RNIB

- The activity on "communicating" has been drafted in a way that excludes visually impaired people who use spectacles or contact lenses to access written information. Again, this shows a lack of understanding about the aids and appliances many blind and partially sighted people use and their fundamental role in enabling independent living. What about people with some useful vision who need specialist spectacles or lenses to access information? Their difficulties accessing written information aren't considered by the draft regulations.
- For the daily living component, the current draft does not give sufficient weight to accessing written information for someone who is partially sighted and on a whole range of activities like "making financial decisions", "engaging socially" and "grooming" someone who is partially sighted would not score any points at all. This simply

makes no sense. It would mean partially sighted people who currently receive the lower rate of DLA (care component), and need that support to live independently, would not be eligible for PIP at all.

- The case studies used by the Government to illustrate how the new benefit will work for people with visual impairment have been chosen to focus on adaptation and change, both in the condition and in how the person deals with it over time. The authors of those case studies are expecting relatively high initial awards, but that most people will 'adapt' - or get equipment or reasonable adjustments - so can be deemed to need less support when reassessed.
- In reality, regardless of the length of time a person has lived with sight loss, the difficulties and barriers remain. Taxi fares, the purchase of specialist equipment and assistance around the home all represent significant ongoing costs for blind and partially sighted people. We fear that there will be routine reductions to PIP allowance after reassessments.

Does the government need to make more changes to this? **Yes**

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

- This is supposed to be *personal independence*; to be able to move 50 metres without a wheelchair is *not* independence.
- It will be the assessor's interpretation of the concept of a condition.
- Unless some one is confined to a wheelchair, it is difficult to assess mobility.
- This is a nonsense in assessing need. It more of a hindrance than a help.
- There is a risk of misinterpretation of need which may lead to legal challenges in the future.
- Challenging behaviour and complex needs will need to be assessed by someone who understands these needs.
- A draft copy of the assessment should be sent to the person for clarification/agreement before it is signed off.

- Assessing people with lifelong disabilities is a waste of time and money.

Does the government need to make more changes to this? **Yes**

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

- Appeals linked to the law, cost of appeals and appeals on the process to judicial review
- 50 metres without a wheelchair will give no independence at all.
- How will the assessment take place and who will do the assessing.
- Will the assessors have targets/quotas to meet?
- Cuts of 20% have to be made and ½ million people will no longer get payments because of the narrow definition of disability.
- Preventative services are being removed, who will pick up the fall out from this.
- GP fund holders need to be alerted to what will happen when these changes are made.
- Points do not reflect the complex needs of someone with e.g. autism/learning difficulties which do not fit the tick boxes.
- Where is the dignity in the questions/points?
- This appears to be personal *dependence* payment not independence.
- Define independence to get a balance of what is needed.
- Assessed needs are not understood.
- Without the enhanced rate people in receipt of DLA will no longer get access to a mobility car or a bus pass. They will become immobile and have to reapply to be assessed again.
- A draft copy of the assessment should be sent to the person for clarification/agreement before it is signed off.
- Assessing people with lifelong disabilities is a waste of time and money.
- Assessing people with challenging behaviour is difficult.

Does the government need to make more changes to this? **Yes**

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

- People with disabilities are being targeted to make cuts.
- Everyone should be reassessed under the current system.
- Assessors are not medical people with an understanding of the condition(s) they may be assessing.
- We do not want the medical model back.
- The points system has no understanding of needs but have targets to reduce uptake – is that a true assessment?
- A draft copy of the assessment should be sent to the person for clarification/agreement before it is signed off.
- Assessing people with lifelong disabilities is a waste of time and money.
- Assessing people with challenging behaviour is difficult.

Does the government need to make more changes to this? **Yes**

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

- This section is totally flawed.
- How will 12 months monitoring be done.
- For people with changeable conditions, each day will be different.
- There are worries about the time period and that people may miss out if help is needed only for 100 days.
- Eligibility will change and people may fall through the net.
- There is a reduction in benefit until an appeal is heard – where is the appeal process?
- This is too - simplistic who will measure it?
- It is over simplifying lifelong conditions.

- There needs to be a box giving more points for those who need 24/7 care.
- Therapy, not just medication, needs to be taken into account. Some people have to be continually prompted, assisted, coaxed to take actions.
- Risk assessment says that if an incident has happened once it will happen again and this must be taken into account.
- What does 'little better' 'little worse' mean?
- There is concern that this is establishing a bench mark to decide if someone is disabled or not; marginalisation will happen and needs will not be met.
- Unmet needs will place a huge burden on continuing health care. Isolation and lack of support can lead to depression and an escalation of medication.
- A draft copy of the assessment should be sent to the person for clarification/agreement before it is signed off.
- Assessing people with lifelong disabilities is a waste of time and money.
- Assessing people with challenging behaviour is difficult.

Does the government need to make more changes to this? **Yes**

**Question 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?

- This section (page 13) needs to stay but as it stands will depend on the perception of the assessor. It more needs more explanation and more teeth.
- What will happen if the assessor does not use this process – what are the consequences?
- It needs to say 'the assessor must use these criteria' and apply it to every question.

- If it is a guideline and not a directive it will end up in the bin. The consultation will then be a waste of our time and money.
- Will evidence be asked for by the assessor?
- Where is the points system for this?
- Who determines what is safe?
- Who judges the assessors assessment?
- Who trains the assessors?
- It is too ambiguous – how will each section be evaluated.
- This process is discriminatory, disempowering and degrading.
- It can induce panic (especially in brain injured people), exclusion and psychological distress.
- There are all sorts of definitions of disabled – who decides who is able?
- Not all disabilities are visible.
- Why are those given a life award not exempt from further assessment?
- A draft copy of the assessment should be sent to the person for clarification/agreement before it is signed off.
- Assessing people with lifelong disabilities is a waste of time and money.
- Assessing people with challenging behaviour is difficult.

Does the government need to make more changes to this? **Yes**

Should the meanings be in the regulations? **Yes**

**Question 8** – What do you think about the way the regulations show the meanings of words.

- Deceptive, misleading, greatly misunderstood.
- It is open to interpretation – so many questions rather than answers.
- Interpretations can be used as definitions in an appeal.
- What does 'bathe' mean? Intimate hygiene is not discussed.
- This is micro managing people's lives and is gross misconduct.



- This is the absolute opposite to choice and control.
- It is too prescriptive and simplistic. It has been written by people who lack understanding and clarity about disability actually means.
- It has been written to enable cuts to benefits to be made and ½ million people will be affected.
- A draft copy of the assessment should be sent to the person for clarification/agreement before it is signed off.
- Assessing people with lifelong disabilities is a waste of time and money.
- Assessing people with challenging behaviour is difficult.

Does the government need to make more changes to this? **Yes**

**Question 9** – Do you want to say anything else about the draft regulations?

- We are heartily sick of repeated consultations being used against us instead of being positively used.
- Why are we not using English political processes and outcomes rather than the American social security structure?
- Why are those given life awards repeatedly assessed without requesting assessment?
- If I am not on DLA am I still regarded as disabled?
- If a person is not claiming and/or in receipt of benefit (PIP) then they are no longer eligible for any other support.
- In some conditions e.g. 'challenging behaviour', meeting with strangers may cause high risk.
- This will never be fit for purpose as it has been designed to cut benefits and the number of those eligible for them.
- If a person is no longer classed as disabled they will lose access to any associated support e.g. blue badge, council tax reduction, attendance at day centres.
- In effect a person who is assessed as disabled today may not be in the future. Is this a miracle? Does the government walk on water?

- What do the government propose to do for those no longer assessed as disabled? What will the government put in place for them?
- The social model of disability has been hard fought for and this process will enforce a medical model on the disabled community.
- We request that an equality impact assessment be done to show what impact the government's actions will have on disabled people.
- This equality assessment is part of policy and should be publically available.
- Will this system be piloted before policy is changed legally?
- A draft copy of the assessment should be sent to the person for clarification/agreement before it is signed off.
- Assessing people with lifelong disabilities is a waste of time and money.
- Assessing people with challenging behaviour is difficult.

Does the government need to make more changes? **Yes**