

Personal Independence Payment: Assessment thresholds and consultation:

Response from Positive East

Introduction to Positive East

Positive East is East London's leading community based charity. The charity supports people living with HIV to promote their health and wellbeing, contributes to reducing late diagnosis and undiagnosed HIV infection, works to eliminate onward transmission of HIV, ensures the voice of people living with HIV is heard in the policy, service improvement and development processes and challenges HIV stigma and discrimination.

Positive East's position is unique because of our long-established links with the communities we work with. No other specialist HIV organisation in London delivers the hands-on work or holds the level of trust that we have built with the communities we work with. Last year our services reached out to over 2,500 people.

Many of our clients are living well due to the effectiveness of treatment and support and are not receiving Disability Living Allowance. However, a significant number of clients do receive Disability Living Allowance and will need to claim Personal Independence payment. These include cases where HIV infection was diagnosed late, with resultant severe long term health problems, or where there are significant side effects from antiretroviral medication. Many have chronic mental health problems, exacerbated by living long term with recurrent health problems, pain, isolation and stigma.

We provide a comprehensive Welfare Rights service to people in matters of incapacity and disability benefits from the claim stage through to representation at Appeal Tribunals. This response is made further to our submission on the first draft of the Personal Independence Payment (PIP) assessment criteria, and alongside case studies and comments submitted to and made with National AIDS Trust.

General Comments

We consider the thresholds for entitlement to the PIP components to be unreasonably high and believe that many of the scores are unreasonably low. See our answers to the Descriptors questions.

Our experience with face to face assessments in Employment and Support Allowance (ESA) cases is that they are usually ineffective in discovering the true

picture of clients' needs. They are commonly based on how the client appears, and are frequently inaccurate and distressing for clients.

Many decisions based on these assessments result at Appeal Tribunals where the success rate of our representation is 95%. Evidence from clients' own health care practitioners consistently contradicts the conclusions made by HCPs at face to face assessments, demonstrating the inadequacy of these assessments. For people living with HIV, needs and difficulties are frequently missed due to lack of understanding of how people are affected by HIV and antiretroviral medication, and assumptions based on outward appearance. This leads to poor decision making, causing clients significant distress, affecting their ability to comply with their antiretroviral regime, and increasing the stigmatisation they feel from having to struggle to disclose the impact of the HIV virus on their lives in the face of not being believed. It also leads to increased poverty and worsening health as they have to wait months, if not years for decisions to be overturned at appeal, with only subsistence levels of income in the interim. We cannot agree that a flawed system is the best way to assess entitlement to PIP.

Feedback from People Living With HIV

We have conducted mock assessments and facilitated a focus group with a range of clients who already receive Disability Living Allowance to obtain their responses to the proposals. They all found the process very stressful as they anticipated problems. They felt that the use of Personal Assessments would lead to an inaccurate understanding of their needs and difficulties. Some of them had experienced assessments as part of the ESA process and felt that the process allowed no more than a snapshot leading to unfair judgements and incorrect decisions. One of the participants concluded,

"DLA has helped me to be independent. PIP is taking away my independence, especially since my situation hasn't improved and is unlikely to improve"

They felt that claimants were assessed more fairly if they had more visible signs of their disability, most often not the case with HIV, and that it was more just to obtain evidence from the professionals working with them, and who know their situation. In several cases where clients have peripheral neuropathy the HCP report has stated that there cannot be a significant problem with walking because there is no evidence of muscle wasting.

They found it very difficult to select the appropriate descriptor without guidance from an adviser. They could not decide what prompting meant, and whether it included coaxing and encouragement, they could not decide whether they should select a descriptor for mobilising based on absolute distance alone or whether they should take account of pain, breathlessness, fatigue. They felt they would have to select a descriptor which reflected that they could heat up a ready meal in the microwave but had been advised by their doctor not to rely on such food.

Personal Independence Payment: Assessment thresholds and consultation:

Response from Positive East: Lynn Johnson: April 2012

They described problems with memory and concentration affecting taking medication and communicating but did not satisfy the strict parameters of the descriptors for these activities.

They were very fearful of the requirement to submit medical evidence within a 4 week deadline; some people had been asked to pay for medical evidence, some doctors had stated that they were too busy to provide it, and some had stated that they would prefer that the DWP requested (and paid for) a report. Some doctors had insisted that they discuss the request in person with their patient, making them wait for an available appointment or referral. Where evidence was provided, it frequently took longer than 4 weeks to obtain.

Response to Consultation Questions

Positive East will focus on the questions in which we have the most experience and expertise.

Q1: What are your views on the latest draft daily living activities?

Q2: What are your views on the weighting and entitlement thresholds for the daily living activities?

We consider that more weight needs to be given to certain activities (see below) as these are crucial to the wellbeing of people living with HIV. There also need to be clearer notes on the claim form as to what is meant by prompting, to include coaxing and encouragement. We consider prompting should be included in all the activities of daily living. We consider that communicating should incorporate problems with memory and concentration.

We consider that someone who needs assistance and supervision for at least one hour every day should be able to obtain the standard rate of the daily living component, because their need is around activities that are vital to their survival such as eating, taking antiretroviral medication and accessing medical appointments.

We consider that there need to be clear notes on the claim form to ensure that night time needs are discovered.

- Activity 1: Preparing food and drink

A claimant should be assessed as scoring 4 points if they can only heat up a prepared meal in a microwave.

- Activity 2: Taking nutrition

There needs to be clarity or information about what is meant by prompting, to encompass encouragement and coaxing. Many clients have no motivation to eat but are required to eat when taking their antiretroviral medication.

Personal Independence Payment: Assessment thresholds and consultation:

Response from Positive East: Lynn Johnson: April 2012

- Activity 3: Managing therapy or monitoring a health condition

Any claimant who needs supervision, prompting or assistance to take antiretroviral medication should score 4 points, not 1, as this treatment is life preserving and requires stringent compliance.

- Activity 4: Bathing and Grooming

The score for prompting and supervision should be 4, not 2. If a claimant with HIV cannot safely bathe due to the risk of injury from falling in the bath or shower, this should be given more weight. Similarly, if they cannot motivate themselves to bathe, there are risks from opportunistic infections.

- Activity 5: Managing toilet needs or incontinence

This activity should include changing clothes as there is no note in Activity 6 to tell claimants to include it there. It is unreasonable and unsafe for people with HIV to be unable to score points for this activity as it is a frequent feature of symptoms and side effects.

- Activity 6: Dressing and undressing

The score should reflect frequency of need, as clients with incontinence, sweats, and skin conditions may need to change several times a day. In these situations the score should be 4, not 2.

- Activity 7: Communicating

Many people with HIV have problems with memory and concentration, as side effects of antiretroviral medication and symptoms of depression and anxiety. These are not reflected in the descriptors; they need help to remember what has been said during and after verbal communication, help to concentrate on what is being said, help to communicate in writing.

- Activity 8: Engaging socially

Clarification is needed to confirm that prompting includes coaxing and encouragement.

It is unreasonable to make an evidence requirement for this descriptor at the outset of a claim; many people with HIV have experienced discrimination and mental health problems to the extent that they are very isolated and frightened to go out. One client in our focus group asked what the laws are regarding social contact for people with HIV. It is difficult for people to access treatment for mental health services; there are long waiting lists and many doctors charge for writing letters. We recently requested a report from a psychiatrist who stated that they would provide one at a reduced fee of £200.

- Activity 9:

Clarification is required in the notes to show that any one of the activities will satisfy the requirement, not all 3.

Q3 /Q4: What are your views on the weightings and entitlement thresholds for the mobility activities?

- Activity 10:

As above, we consider that the need to provide evidence at the claim stage of the process is unrealistic and unjust. Also, the term "prompting" needs to be clarified to include encouragement and coaxing.

- Activity 11:

There needs to be provision for the impact of pain, severe discomfort and breathlessness on moving around. There needs to be provision for the danger from falls in one of the mobility descriptors, and provision around the cumulative effect of walking on the claimant's health, for example if walking 50 or 200 metres will require the claimant to rest for the remainder of the day.

Q7: What are your views on the definitions of safely, timely, repeatedly, in a timely manner?

It is important to ensure that claimants are made aware that these definitions apply to all of the descriptors, and that the definitions are incorporated into the regulations.

Q9: Do you have any other comments on the draft regulations?

Any activity which can only be done with pain and/or severe breathlessness is one where assistance is required.

We consider that valuable and tested case law that has developed from Disability Living Allowance should be incorporated into PIP.

Lynn Johnson

Welfare Rights Worker
Positive East

E: lynn.johnson@positiveeast.org.uk
T: 020 7791 9373 (Direct line)

A: Positive East, 159 Mile End Road, London E1 4AQ

Positive East is a registered charity: 1001582.