



## Personal Independence Payment Assessment thresholds consultation

April 2012

- 1.1 Terrence Higgins Trust (THT) is the UK's largest HIV and sexual health charity, with 32 service centres across England, Scotland and Wales. THT is a membership and campaigning organisation which works with and advocates on behalf of people living with or affected by HIV. A proportion of our work involves providing advice and support to people who need to access the benefits system. We provide welfare advice and support with advocacy in appeals, as well as, guidance on securing employment and overcoming barriers such as discrimination in the workplace.
- 1.2 This response has been produced in consultation with our welfare advisers and their clients across the country who undertook a draft assessment exercise to identify potential strengths or problems with the PIP assessment thresholds. We undertook around 20 mock assessments between February and April 2012 with people living with HIV who are currently in receipt of DLA. A number of trends and issues emerged from this exercise which we will outline in this response.
- 1.3 We welcome this consultation and believe that direct engagement of this kind is necessary to ensure that the assessment criteria and processes for Personal Independence Payment are as equitable, responsive and relevant as possible. We also consider it essential that the mistakes made in the implementation of ESA and the Work Capability Assessment are not replicated in the PIP process. We therefore urge the Department of Work and Pensions to seriously consider the points raised in this response in order to ensure that vulnerable people are not further disadvantaged by the PIP assessment process.
- 1.4 We also need to state our opposition to the aim of a 20% reduction in DLA/PIP claims, or 500,000 reduction in claimants. This is an entirely arbitrary figure and will create considerable anxiety and stress for many people who are legitimately in receipt of DLA. Equally we do not support the plan to reassess most claimants. We believe that more emphasis should be placed on gathering evidence

**from care professionals who have a thorough understanding of a person's condition, and that face to face assessments should only be carried out where there sufficient evidence to warrant it.**

Question 1. What are your views on the latest draft Daily Living activities?

Question 2. What are your views on the weightings and entitlement thresholds for the Daily Living activities?

Question 5. What are your views on how the regulations work regarding benefit entitlement?

#### Activity 1. Preparing food and drink

- 2.1 Terrence Higgins Trust is strongly opposed to the inclusion of the phrase 'but can do so using a microwave' in by descriptor C in Activity 1. Currently the DLA cooking test recognises that a proper meal cannot be created using a microwave and it must be made from fresh ingredients and cooked by other means. Microwave and fast foods do not constitute a meal in DLA case law.
- 2.2 For people living with HIV nutrition is hugely important to their health and wellbeing. HIV is an immune disorder and people living with the virus need to maintain a high level of nutrition to keep their immune system as strong as possible. The vast majority of processed or microwavable meals will not provide adequate nutrition for people living with HIV. Quality microwavable meals are also significantly more expensive. This provides a useful example of how having a disability can bring extra costs to your daily routine. It is exactly these additional costs that DLA was devised to help meet.
- 2.3 We would strongly encourage the DWP to remove this descriptor as microwavable meals are not a sufficient substitute for proper nutrition and this should not be used as justification to award less points to a claimant. We would also strongly suggest that the points awarded in descriptor D in this activity: 'Needs prompting to either prepare or cook a simple meal' should be increased to at least 4.

#### Activity 2. Taking Nutrition

- 2.4 We would also strongly support an increase in the points for descriptor D in Activity 2, 'Taking Nutrition'. Being able to take nutrition is one of the most important means by which people living with HIV can effectively manage their disability. Terrence Higgins Trust believes that

the implications for someone failing to take nutrition are so severe that this descriptor should carry 8 points.

### Activity 3. Managing therapy or monitoring a health condition

- 2.5 Adherence to medication is a vital issue for people living with HIV. Failure to take medication every day at an allotted time risks an increase in HIV viral load, damage to a person's immune system and developing drug resistance. All of these issues can cause very severe consequences for a person's ability manage their HIV and their health.
- 2.6 The fact that PIP will only award 1 point to a person living with HIV who 'needs supervision, prompting or assistance to manage medication, is unfair and unrepresentative of the importance of this activity. Adhering to medication is the single most effective way that people living with HIV can maintain their health and prognosis. The fact that PIP fails to recognise this is of significant concern.
- 2.7 The points awarded for the descriptor B in Activity 3 must therefore be increased. In instances where failure to manage medication can have a life threatening impact we believe that this descriptor should carry 8 points. The 14 hours required is arbitrary and too high a threshold. It does not recognise people who may only need to be reminded once a day, but to whom adherence to medication in that instance is vital.

### Activity 5. Managing toilet needs or incontinence

- 2.8 During our trialling of the draft assessment it became apparent that many people with HIV in receipt of DLA where potentially subsidising and meeting mobility costs through care related DLA payments. A significant number of people living with HIV told us that difficulty in managing toilet needs and incontinence led to mobility problems and limited their ability to take journeys without the aid of a taxi or car.
- 2.9 HIV medication can cause severe and sudden diarrhoea or evacuation of the bowels. In many instances people living with HIV in receipt of DLA reported being unable to leave the house or only being able to take very short journeys by car. This need is not properly represented in either Activity 5, or in the mobility activities and we would urge the DWP to address this. We feel that this would most appropriately be addressed in the mobility section. However, it should also be acknowledged within Activity 5 by ensuring that descriptor E 'needs assistance to manage incontinence of either bladder or bowel' covers limitations on mobility, engaging socially and experience of incontinence during the night.

Activity 7. Communicating/ Activity 9. Making financial decisions

2.10 We remain unclear as to whether this activity refers only to people who have sensory difficulties. Within DLA a person can claim where help is needed in answering and making phone calls, completing forms, and dealing with their affairs more generally. It is unclear whether these needs are represented in either of Activities 7 or 9. We would suggest strongly that they should be incorporated into one of the descriptors or in the regulations for Activity 7 and or 9.

2.11 Activity 9 does not include anything on requiring assistance with basic financial management. This should also be addressed.

Question 3. What are your views on the latest draft Mobility activities?

Question 4. What are your views on the weightings and entitlement thresholds for the Mobility activities?

Question 5. What are your views on how the regulations work regarding benefit entitlement?

3.1 We remain very concerned that the PIP assessment descriptors on mobility have a very narrow focus. Many people living with HIV can experience difficulty in getting around due to a range of factors such as peripheral neuropathy, severe joint pain, acute anxiety or incontinence. PIP should be available to help this group stay active by helping to pay for appropriate transport and assistance as needed.

Activity 10. Planning and following a journey

3.2 The definition of overwhelming psychological distress used in this Activity needs to be revised as it does not adequately recognise anxiety or panic attacks which can be significantly disabling. We would also urge that anxiety and stress caused by a fear of incontinence of the bladder or bowel be included in this definition.

Activity 11. Moving Around

3.3 This activity must make clear that pain, fatigue, breathlessness and incontinence should be considered in assessing a claimant. DLA currently recognises the impact that severe discomfort, including pain and breathlessness

and incontinence, has on people's walking ability. (See also point 2.8/2.9)

3.4 The PIP descriptors for Activity 11 are similar to the assessment for Employment and Support Allowance. HIV-specialist welfare advisers are reporting that it is only those people living with HIV who cannot walk at all who are found eligible for ESA under this activity. It is essential that PIP recognises the impact of severe discomfort on people's ability to walk and the distance, speed and manner in which they walk. We would strongly urge the DWP to ensure that this is detailed clearly in the regulations for PIP to ensure that people who struggle to walk are fairly assessed under PIP.

3.5 The questions are similar to ESA but appear to be tougher in that they require an aid for the most part. In DLA claimants qualify if they are found to be virtually unable to walk if they cannot move more than 50 metres without severe discomfort limiting the time, speed distance and manner in which they walk. Some people with HIV currently meet DLA criteria due to HIV related neuropathy, joint pain and fatigue. It is unlikely that they will pass the new criteria for PIP.

3.5 During our trialling of the assessment we encountered a number of individuals who encountered severe difficulty in mobilising, but whom may only qualify for standard rate PIP or no award because the descriptors do not appear to take account of pain or discomfort. These include:

- A claimant who uses a crutch and can mobilise 200 metres but only in either pain or severe discomfort who could potentially score 0 under Activity 11.
- A claimant who has severe difficulty mobilising. He requires a taxi card to help him to get around safely as using public transport is too dangerous. Under this criteria he would not qualify for enhanced rate and may lose his taxi card entitlement also.
- A claimant who has difficulty planning a journey to a place that she is unfamiliar with and judging timing. She does not go to places she does not know well because of anxiety. She previously qualified for low rate mobility under DLA but will now be isolated. She also needs to stop to rest every 50-200 metres due to back pain and fatigue.

Question 6. What are your views on how we are dealing with fluctuating conditions?

- 4.1 Terrence Higgins Trust is disappointed that the preventative purpose of DLA is set to be lost. Currently DLA allows people with disabilities to secure small amounts of care and support which can prevent them from developing more intensive support needs. Access to social care services in the UK require a high level of need in most cases and DLA has worked to provide a safety net for those disabled people, including many people living with HIV, who have some support needs in their day to day lives, but who do not currently qualify for more intensive social care.
- 4.2 Terrence Higgins Trust is extremely concerned that PIP does not appear to have the same preventative purpose as DLA and that people with lower level needs will be left without support. In many cases this will mean that people's conditions will deteriorate and they could go on to develop more severe problems which will eventually, after time, qualify them for PIP, potentially at a higher rate. This is a false economy and will leave many disabled people, including people living with HIV, in an unacceptably vulnerable position. We are disappointed that disabled people could be made vulnerable in order to make short term savings for the Government.
- 4.3 We would welcome further clarity on how someone with a fluctuating condition such as HIV would be assessed and what evidence would be required regarding the percentage of time a person has fits a descriptor. We are concerned that this could give way to arbitrary decision making.
- 4.4 We also consider that the approach to acute and unpredictable episodes which is applied in the case of epilepsy should apply to all people with fluctuating conditions.**

Question 7. What are your views on the definitions of 'safely', 'timely', 'repeatedly' and 'in a timely' manner?

- 5.1 Reliably, repeatedly, safely and in a timely manner are vital to understanding the assessment and ensuring it is fair. They should therefore be placed on the face of the regulations.

Question 9. Do you have any other comments?

We are concerned that there appears to be little in the proposed criteria to assess:

- Getting in and out of bed.
- Moving around safely indoors
- Night time needs in bed
- Night time needs in terms of supervision

Night time issues for people with HIV can range from:

- Nightmares resulting from medication or worries about their health/death
- Night sweats (need to change sheets to sleep properly-healthily)
- Night time incontinence (changing sheets)
- Getting to toilet at night because they are too drowsy or tired to make it safely to the toilet.

Finally we would like to urge the DWP to take clear action to ensure that assessors and decision makers receive relevant training and information on HIV to allow them to make fair and accurate assessments. Currently too many people living with HIV report poor experiences of assessments for Employment and Support Allowance, in particular, and HIV organisations have expressed concern about the quality and accuracy of the information and training made available by the DWP and contracted organisations. It is vital that the DWP learn from the problems with the Work Capability Assessment and ensure these aren't repeated with the new PIP assessment.

#### Recommendations

It is vital that the preventative purpose of DLA is reflected in the purpose of PIP.

The DWP should remove descriptor C in Activity 1

The points awarded in descriptor D in Activity 1: should be increased to at least 4.

The points for descriptor D in Activity 2, 'Taking Nutrition' should be increased to 8.

Points awarded for descriptor B in Activity 3 must be increased. In instances where failure to manage medication can have a life threatening impact we believe that this descriptor should carry 8 points.

Descriptor E in Activity 5 must ensure that 'needs assistance to manage incontinence of either bladder or bowel' covers limitations on mobility, engaging socially and experience of incontinence during the night.

Activity 9 does not include anything on requiring assistance with basic financial management. This should be addressed.

The definition of overwhelming psychological distress used in Activity 10 needs to be revised as it does not adequately recognise anxiety or panic attacks which can be significantly disabling. We would also urge that anxiety and

stress caused by a fear of incontinence of the bladder or bowel be included in this definition.

Activity 11 must make clear that pain, fatigue and breathlessness and incontinence should be considered in assessing a claimant. DLA currently recognises the impact that severe discomfort, including pain and breathlessness and incontinence, has on people's walking ability

Further clarity is needed on how someone with a fluctuating condition such as HIV would be assessed and what evidence would be required regarding the percentage of time a person has fits a descriptor. We are concerned that this could give way to arbitrary decision making.

**The approach to acute and unpredictable episodes which is applied in the case of epilepsy should apply to all people with fluctuating conditions.**

The following issues should be assessed within the criteria:

Getting in and out of bed.  
Moving around safely indoors  
Night time needs in bed  
Night time needs in terms of supervision

For further information on this response contact Catherine Murphy at [catherine.murphy@tth.org.uk](mailto:catherine.murphy@tth.org.uk) or call 02078121600