



## **Personal Independence Payment: Draft assessment criteria**

### ***Response from NAT (National AIDS Trust)***

NAT welcomes the opportunity to respond to the Department for Work and Pensions (DWP) informal consultation on the draft assessment criteria for Personal Independence Payment (PIP).

NAT is the UK's HIV policy and campaigning charity. We develop policies and campaign to halt the spread of HIV and improve the quality of life of people living with HIV. Policy and advocacy related to the needs of socially disadvantaged communities in the UK forms an important element of our work, and this includes people living with HIV who rely on benefits.

NAT is a member of the Disability Benefits Consortium (DBC), and we support the DBC's submission to this consultation.

Our response draws on our experience reviewing the Work Capability Assessment (WCA). We were part of a working group, chaired by MS Society, which was invited to provide recommendations on how the WCA could be refined to more accurately assess people with fluctuating conditions, including HIV. As the draft PIP assessment takes a very similar format to the WCA, these recommendations - and Professor Harrington's recommendations from the independent review of the WCA - should be taken into account in the development stages.

NAT accepts in principle an assessment which uses appropriate proxies for an individual's ability to participate in everyday life, in order to determine eligibility for extra costs help to overcome barriers to participation. However, we strongly disagree with the choice of functional descriptors, focusing on physical and mental capacity to carry out particular activities, to act as such proxies.

Instead of the tick-box approach to descriptors, where varying levels of impairment attract different scores, the PIP assessment should ask more open-ended questions about barriers to carrying out key activities. The responses from the claimant and their medical evidence would be a stronger indicator of their support needs and extra costs than the cumulative score of impairment-based descriptors. For a list of activities which should be included, NAT recommends DWP give serious consideration to the DBC's alternative PIP assessment, outlined in the DBC submission.

However, as the DWP has shown a preference for the descriptor-driven approach, we have also provided comments on each of the proposed descriptors, with recommendation for how these can be modified to better reflect the barriers to participation faced by people living with HIV.

We were pleased to hear the DWP's plans to engage with disabled people and the organisations that support them and to test the PIP assessment prior to

implementation. NAT would like to highlight the barriers to engagement for many people living with HIV (because of the stigmatised nature of the condition) and would welcome the opportunity to be involved in these processes to ensure they achieve meaningful involvement of people living with HIV.

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**Note on case studies**

*All case studies and examples used are real, although they have been anonymised.*

*The quotes included in this submission are drawn from a variety of sources including:*

- *the DBC survey on disability benefits (the basis of the DBC report, Benefitting disabled people?);*
- *an NAT survey of 265 people living with HIV who experience fluctuating symptoms (report forthcoming);*
- *and an NAT call for evidence on DLA/PIP from people living with HIV and their support organisations.*

## 1. Functional proxies do not assess participation

- 1.1. The technical note on the draft assessment explains that it uses “proxies for an individual’s ability to participate in everyday life” as an indication of the additional costs that may be faced. NAT agrees with this approach in principle. The existing DLA assessment also takes this approach, asking claimants who attend medical assessments questions such as:

*Do you have any problems with using the toilet?  
Can you prepare a meal for yourself using the cooker?  
Do you need anyone with you when you are out?  
Do you go out socialising?*

- 1.2. However, the approach to the proxies in the proposed PIP assessment is much more focused on specific functions. These necessarily make the focus of the assessment **severity of impairment**.

- 1.3. Instead of capturing any relevant evidence about difficulties the claimant may have with, for example, using a toilet, and the likely impact of this on their independence and participation, the assessment considers five specific **physical functions**:

- A. Can manage toilet needs or incontinence unaided.
- B. Can manage toilet needs or incontinence only with the use of an aid or appliance.
- C. Can manage toilet needs only with continual assistance.
- D. Can manage incontinence of either bladder **or** bowel only with continual assistance.
- E. Can manage incontinence of both bladder **and** bowel only with continual assistance.

As such, the descriptors end up being a proxy for level of impairment, rather than a meaningful measure of likely barriers to participation or an indication of how assistance in the form of PIP could facilitate greater independence and inclusion.

- 1.4. This is not in line with the social model of disability which DWP stated would inform the PIP assessment. An assessment based on the social model would take into account medical and social drivers of exclusion, not just how physical and mental functionality predicts ability to carry out certain daily activities.
- 1.5. The activities considered by the assessment are far too limited to be considered proxies for participation and inclusion. They are proxies for a basic existence – eating, bathing, taking medication, and moving around – and not the costs associated with an active, independent life. It is an atomistic view of the individual, without reference to the social determinants of their participation, such as access to personal networks, ability to engage in social activities, and availability of formal and informal forms of support.
- 1.6. In addition, the inclusion of various levels of either ‘assistance’ or ‘prompting’ in each descriptor means that the new ‘daily living’ descriptors are in fact

making demonstrated care needs core to eligibility – this is at odds with the decision to move away from the current DLA approach of using care as a proxy.

## Recommendations

**The PIP assessment must move away from a focus on the impact of impairment, as shown in the draft criteria, to a broader understanding of the social as well as medical determinants of participation.**

**The descriptors for the daily living component should be modified to ensure they do not in effect act as a proxy for care needs.**

## 2. Fluctuating and complex conditions

2.1. The draft criteria do not reflect the guiding principle of the PIP assessment development of “accurately capturing the impact of variable and fluctuating conditions and ensuring that an individual’s safety is paramount in all cases”.

2.2. The technical note explains that to take into account fluctuation the assessment will:

- consider whether the descriptor applies for at least 6 out of 12 months in the assessment period; and
- score the descriptor based on the need that applies the majority of the time.

To only focus on difficulties which are faced half the time or more is an imprecise and misleading approach to fluctuation, which will lead to inaccurate assessments of need. Professor Harrington noted this in his review of the Work Capability Assessment (WCA), which takes the same approach.

2.3. Even if a barrier to participation is experienced only a minority of the time, it can incur significant additional costs to overcome – indeed, the unpredictability of some symptoms may create additional costs. For example, if a claimant is using their DLA to help pay for a carer, it is unlikely that they will have the flexibility to not pay for the carer on the days that they feel well enough to manage alone. For complex conditions like HIV, fluctuating symptoms which are not experienced the majority of the time may still be severe enough to impact on participation as much as more consistent, lower-level needs.

*One service user noted that her pain can be seasonal- if it is cold or raining, sometimes she can feel a lot worse. For example, her arthritis worsens when it is cold weather. Her balance also feels less steady when it is cold or wet, which impacts on whether she feels able to leave the house.*

- HIV support service project coordinator

- 2.4.** The technical note indicates that all activities considered by the assessment must be able to be carried out ‘reliably, in a timely fashion, repeatedly, and safely’. However, these do not appear on the face of the descriptors that will be used. The experience of the WCA has shown that if this wording is not included directly in the descriptor, it will not be consistently considered in assessment. The experience of the WCA has also shown the importance of providing guidance to assessors on what this means – e.g. the ability to safely prepare three meals a day, every day, without assistance.
- 2.5.** Some descriptors differentiate between whether someone needs ‘continual’ or ‘intermittent’ assistance or prompting in order to carry out the activity. In others, points are **only** allocated where ‘continual’ assistance or prompting is needed (planning and buying food and drink; preparing food and drink; managing medication and monitoring health conditions; washing, bathing and grooming; managing toilet needs or incontinence). This automatically excludes claimants with needs which are severe but not constant.
- 2.6.** This new terminology has replaced the concept of ‘supervision’ needs currently used in assessing DLA eligibility for both the mobility and care components. Supervision was well understood by advisers and easy to understand for claimants, and could apply to those with fluctuating conditions as well as those with more constant needs. Separating out this concept to make distinctions between the need for ‘assistance’ versus ‘prompting’ on a continual or intermittent basis adds complexity and the possibility for confusion, which may lead to claimants’ needs being overlooked.

## **Recommendations**

**When considering fluctuating conditions the assessor should consider the impact of impairment that occurs a significant minority of the time, not just the majority. The impact of the impairment should be judged in terms of its affect on participation and independence, not what proportion of the time it is experienced.**

**The words ‘reliably, in a timely fashion, repeatedly, and safely’ should be included on the face of each descriptor.**

**Detailed guidance should be provided to assessors for each descriptor on how to assess if the activity can be carried out ‘reliably, in a timely fashion, repeatedly, and safely’.**

**The DLA concept of ‘supervision’ should be retained, with guidance on how it is applied to fluctuating and complex conditions, rather than differentiating between ‘assistance’ and ‘prompting’.**

### **3. Scoring of the descriptors**

- 3.1.** While NAT already has specific concerns about the draft descriptors, it is very difficult to respond properly to the proposed assessment until information about the scoring system is provided. In commenting on the impact of the assessment on people living with HIV, it is crucial to know if claimants who face real barriers to participation would be found ineligible based on what is a fairly arbitrary scoring formula. Given the similarities between this assessment and the WCA, we anticipate that the threshold set for PIP may be too high, meaning that people with HIV who currently rely on DLA to lead active, independent lives will be excluded from participation in future.
- 3.2.** We question the appropriateness of scoring descriptors differently based on how severely impairment limits the claimant's ability to carry out an activity. Under the draft assessment a claimant will be given one of four or five possible scores for each descriptor. As such, claimants will essentially be ranked according to their level of impairment. This adds a significant layer of complexity, as compared to the DLA assessment.
- 3.3.** DWP has not provided any explanation of how this will help identify the support needs of disabled people who have barriers to participation. For example, on the 'moving around' descriptor, the claimant who is scored on the level 'B' descriptor and the claimant scored on the level 'F' descriptor both have barriers to participation and would clearly incur extra costs in addressing these. However, B is ranked such that it would attract potentially significantly fewer points than F.
- B: Can move at least 50 metres but not more than 200 metres either unaided or with the use of a manual aid
- F: Can move up to 50 metres only with the use of an assisted aid.
- 3.4.** We are very concerned by the emphasis in the technical note on priority for those with 'greatest' needs or challenges. It states that the assessment "should enable us to target Personal Independence Payment on those who need it most". Again this ranking of impairment and barriers is unhelpful. While it is clearly necessary to have a means of distinguishing between standard and enhanced rates based on two levels of likely costs, the current scoring proposal seems likely to go beyond this to excluding disabled people with support needs who are not considered to have severe enough challenges. Again, this does not take a social approach to disability, nor does it fulfil the DWP's stated aspiration to "treat people as individuals" in the assessment.
- 3.5.** It may be practical to introduce a scoring system in order to differentiate between those suitable for standard rate PIP and those in need of enhanced rate. However, this should be applied after the daily living or mobility need has already been identified using a more open-ended assessment based on the information provided by their claimant and their medical evidence.

## Recommendations

**DWP needs to release the proposed scoring of the descriptors. Without this, any response from disabled people and the organisations who support them cannot be fully informed.**

**PIP should be available to any person with a disability or health condition who experiences a significant and observable barrier to participation. To assess this need does not require the comparative dimension currently implicit in the descriptor scoring.**

**Scoring should only be used to differentiate between standard and enhanced rates of PIP, and only after eligibility for one or other component has already been identified.**

## 4. Comments on draft descriptors

### *Daily Living component*

#### 4.1. Planning and buying food and drink

- 4.1.1. More than half of DLA claimants with HIV surveyed said that buying food was one of the top three uses of their benefit.<sup>1</sup> Maintaining a good diet is crucial for people living with HIV. Fighting off infections with a compromised immune system increases the need for energy and therefore food, at the same time that essential medication may trigger nausea and gastro-intestinal problems. As such, both the quality and quantity of fresh food available is important, and dietary supplements may also be necessary. Both add significant additional costs, especially for people on low incomes or reliant on out of work benefits.
- 4.1.2. Using DLA to pay for these special health-related food needs is a cost-effective intervention against subsequent ill-health (which could lead to the need for higher rates of support in future), as well as helping people with HIV stay well enough to participate fully.
- 4.1.3. The draft descriptor on 'planning and buying food and drink' does not consider these special needs and additional costs. Points may only be scored for difficulties with planning the purchase of food and drink. Cognitive issues with planning will not be an issue for the majority of people living with HIV, but many will still face barriers to buying the food they need for their health related needs.
- 4.1.4. As well as direct financial barriers to purchasing sufficient food and drink, people living with HIV may not be able to go to a supermarket due to mobility problems and/or lack of public transport routes. With online shopping, supermarket orders can be delivered, but this also comes at a cost of around £4, which is a significant proportion of a shopping budget for someone on a low income. Convenience stores, which are more likely to be within short

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<sup>1</sup> Analysis of anonymous online survey data collected for the DBC report *Benefiting Disabled People?* (March 2011) <http://www.disabilityalliance.org/dbcreport.pdf>

walking distance, are more expensive and less likely to have the sort of fresh foods needed.

*If I do the supermarket shopping (which entails an hour's bus ride just to get there) I know that by the time I get home (I use the home delivery service) I will be finished for the day. I don't eat ready meals, but instead cook from scratch in large batches to freeze for later.*

-Person living with HIV

- 4.1.5. We are also concerned about how this descriptor will interact with the second descriptor, preparing and cooking food. If someone living with HIV who can use a microwave (but not a cooker) is not found to have severe enough needs to be eligible for PIP assistance, they will be forced to rely on less healthy food options such as ready meals. As well as being insufficient to meet all of their health-related nutritional needs, these meals are more expensive.

### **Recommendation**

**The descriptor on buying food and drink needs to consider barriers to access which are not limited to the ability to plan a meal. For people living with HIV, nutrition is an important aspect of maintaining good health, and the additional costs associated with this should be recognised in assessing eligibility for PIP.**

## **4.2. Preparing and cooking food**

- 4.2.1. We are concerned by how the new descriptor on preparing and cooking food takes the simple and easy to apply DLA test of 'preparing and cooking a main meal (not a ready-made meal or convenience snack)', with a list of activities describing different levels of ability including making a sandwich, using a microwave, and using a conventional cooker.
- 4.2.2. Each of these activities will attract a different number of points. We are concerned that this will mean that someone who is able to make a sandwich or use a microwave without assistance or prompting, but would need help to cook a main meal from scratch safely, will not attract enough points to receive PIP.

*When I cook I do need someone with me, or the place gets flooded, gas gets left on etc. Suffice to say I am not really cooking the meal, I am being humoured while I pretend I am - but that's fine by me, I am safe.*

-Person living with HIV

## Recommendation

**Ranking descriptor points based on the complexity of the food preparation task involved and whether 'prompting' or 'assistance' is required means that people with real difficulties may not be found eligible for PIP. A claimant who can show they are unable to safely prepare and cook a meal on a conventional cooker, even if they can prepare a snack or ready meal, should be able to access PIP.**

**4.3. Taking nutrition** - NAT has no specific comments on this descriptor

### **4.4. Managing medication and monitoring health conditions**

4.4.1. NAT welcomes the consideration of managing medication in the PIP assessment. Adherence to medication is central to living well with HIV. If antiretroviral treatment (ART) is not taken consistently as directed, the individual will become unwell. They are also more likely to pass on HIV when they are not adhering to ART. In addition, poor adherence to ART can lead to the development of drug resistance and the need for more expensive retreatment options in the future.

4.4.2. However, the proposed descriptor on managing medication does not identify all of the relevant factors and costs involved in ensuring that someone living with HIV is supported to adhere to their medication.

4.4.3. One of the main omissions is the lack of consideration that while all essential medications are life-preserving and/or health-promoting, not all medications have the impact of making the patient 'feel better' all of the time. ART, while highly effective, is associated with a range of common side-effects. A survey of over 250 people living with HIV showed that HIV treatment was a main factor in the experience of symptoms such as fatigue, gastro-intestinal problems, neuropathy (nerve damage) and depression and anxiety. For example, 73% of those experiencing gastro-intestinal problems such as nausea, vomiting and diarrhoea and two-thirds of those experiencing neuropathy said that their treatment was a cause of their symptoms.<sup>2</sup>

4.4.4. Experiencing severe side-effects, either on a regular or unpredictable basis, has a psychological as well as physical impact. In addition, people with HIV are disproportionately affected by mental health issues such as depression and anxiety.<sup>3</sup>

*My medication causes very vivid dreaming and sometimes hallucinations/night terrors which can be very distressing. It also can cause feelings of vertigo and being 'spaced out' and I find that if I make changes in my routine this becomes more prominent and can lead to confusion, anxiety attacks, and unsteadiness on my feet. Occasionally in the past I have needed assistance at night as I have got up whilst asleep and have fallen over or walked into things and I often need convincing by someone that the 'visions' I have seen (which can be very real and often scary and confusing) are not real and that I am safe.*

-Person living with HIV

<sup>2</sup> Forthcoming NAT report on Fluctuating Symptoms and HIV.

- 4.4.5. The technical note to the draft PIP assessment notes that mental and cognitive problems will be given greater consideration, as compared to the DLA test. However, in this descriptor the impact of mental health factors in managing medication is limited to the need for 'continual prompting'. This is an extremely narrow and impairment-focused conception of how people with mental health problems may need to be supported to manage their treatment needs.

*I am not sure what 'continual promoting' means...sounds close to harassment.*

-Person living with HIV

- 4.4.6. For people living with HIV who need some psychological support in order to manage their treatment needs, this help will rarely take the form of 'prompting', which implies either cognitive difficulties with understanding and managing a treatment regime, or resistance to engage with an essential treatment regime. Instead, DLA may at present help support someone with HIV to connect with a full range of psycho-social support, including but not limited to peer support programmes and support groups, counselling services, and informal social networks. Simply by meeting the extra costs associated with participating in social activities such as these, DLA can help support the mental and emotional wellbeing of someone living with HIV who is having difficulties adhering to a challenging treatment regime.
- 4.4.7. In addition to the very limited understanding of support outlined in the descriptor, we are disappointed that this descriptor and the one following it, managing prescribed therapies other than medication, are the only two activities to be classed as 'low scoring' in the draft weighting of descriptor points. This undervalues the importance of managing essential treatment to avoid deterioration of health (and the creation of greater support needs), and to promote independence and participation.

### **Recommendations**

**The descriptor on managing medication and monitoring health conditions needs to incorporate an appreciation of the impact of challenging treatment regimes, including those which cause severe side-effects, on the ability to manage medication.**

**The descriptor on managing medication and monitoring health conditions should consider a broader range of types of psychological support when considering whether a claimant will need support from PIP to manage their medication.**

**The descriptor on managing medication and monitoring health conditions should be medium scoring.**

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<sup>3</sup> NAT. 2010. Psychological support for people living with HIV'. [www.nat.org.uk](http://www.nat.org.uk)

#### 4.5. Managing prescribed therapies other than medication

- 4.5.1. We have the same concerns about the scoring given to this descriptor as raised above, especially as it may impact those who are accessing prescribed mental health therapies.

#### Recommendation

**The descriptor on managing prescribed therapies other than medication should be medium scoring.**

#### 4.6. Washing, bathing and grooming

- 4.6.1. The descriptor on washing, bathing and grooming takes an extremely narrow view of the hygiene needs of disabled people, with no reference to the social context of these needs beyond the 'social acceptability' of 'self neglect'. These extremely high thresholds do not promote participation and inclusion - in order to be involved with employment, volunteering or any form of social activity, it is important to dress and groom to an appropriate standard, as well as feel confident. Someone who needs support to dress and groom so that they look smart enough to participate in work or other social activities should be able to access this, without having to be at a level of 'self neglect' to do so.
- 4.6.2. Moreover, the descriptor only assesses how mental or physical impairment affects the claimant's ability to wash, bath and groom their own body. It does not take into account the ability to maintain hygiene beyond the body. This would include washing clothes and keeping a clean living environment.
- 4.6.3. For people living with HIV, washing clothes and bedclothes can be a frequent and demanding chore, as night sweats are a common side-effect of medication. For someone who experiences fatigue, pain or problems with lifting or manual dexterity, changing and washing linen and clothes several times a week is extremely difficult without help. Nor will everyone have access to their own washing machine, let alone clothes dryer. Accessing a laundrette is not an option for those with mobility problems and can be very expensive (at least £3 per load at shops in London). One of the common reasons that people living with HIV approach charity hardship funds is to help with purchasing a washing machine or dryer.<sup>4</sup>

*I get night sweats. I am too tired to do anything, wishing I had the support of family or someone close to help me around the house or for a bit of company even. Being alone with this diagnosis is not easy. I struggle to find the time to keep changing bed linen, having hot baths, getting time for cooking, looking after my child- it's quite demanding...*

- Person living with HIV

<sup>4</sup> See NAT and THT. 2010. Poverty and HIV: 2006 to 2009. [www.nat.org.uk](http://www.nat.org.uk)

- 4.6.4. People with HIV who experience problems with mobility, dexterity, upper and lower limb movements and bending, pain and fatigue will also find it challenging to keep their home clean without assistance. In the case of fatigue, it may be that someone living with HIV is able to work, but is then too exhausted to do anything else. Having support with household cleaning would help them stay in work. Without any help, they may not be able to maintain both their employment and their health.

#### **Recommendation**

**The costs associated with household cleaning, including washing clothes and bed linen are key aspects of hygiene and should be considered in the descriptor on washing, bathing and grooming.**

#### **4.7. Managing toilet needs and incontinence**

- 4.7.1. Gastro-intestinal problems, including diarrhoea, are a common symptom for many people living with HIV, often a side-effect of medication. This means that immediate access to a toilet is a key concern.
- 4.7.2. NAT is concerned that the descriptor on managing toilet needs and incontinence does not take into account any difficulties experienced in getting to a toilet while in the home. This is often more difficult at night time, and some people may need assistance with this. If not specifically dealt with in this descriptor, ability to move around the home should be considered elsewhere in the assessment.

*Why is night time no longer considered to be a more difficult time than day time? It's not. Getting to the toilet when one is up is easier than doing so when in bed, which is where people usually are at night and without access to the help and support they may be able to access in the day time.*

- Person living with HIV

#### **Recommendation**

**The ability to get to a toilet should be considered in the descriptor, managing toilet needs and continence. Alternatively, moving around in the home more broadly should be considered in the PIP assessment.**

#### **4.8. Dressing and undressing**

- 4.8.1. It is not clear from the descriptor how severe the impairment to the lower body or upper body would be in order to be considered to have barriers with dressing and undressing.

#### **Recommendation**

**Further information is needed on how to interpret the severity of lower limb and upper limb impairment when scoring the descriptor on dressing and undressing.**

#### 4.9. Communicating with others - NAT has no specific comments

### ***Mobility Component***

#### 4.10. Planning and following a journey

- 4.10.1. As in the descriptor on purchasing food, the descriptor on planning and following a journey considers a very narrow range of barriers, in this case apparently linked to learning disabilities, cognitive or sensory impairment. The descriptor does not act as an effective proxy in measuring the full range of disability-related costs in making a journey.
- 4.10.2. People with HIV who face access barriers to making a journey will often need to spend more in order to make their journey. The obvious example here is paying for taxis. Taxis may be needed because there are not accessible public transport routes. In London, which has a high HIV prevalence, not all public transport routes are accessible to those with mobility difficulties. Those who live in more rural areas may not be able to access public transport because there aren't routes near enough to their house, or frequent enough buses to meet their needs with attending, for example, clinic appointments. For those who experience pain due to neuropathy or lipodystrophy,<sup>5</sup> it may not be possible to ensure a bus trip of a half hour with frequent stops, but a taxi will reduce travel time to 10 minutes. Access to transport is essential to independence and participation and PIP should help cover the costs of this.

#### **Recommendation**

**The descriptor on planning and following a journey should consider physical barriers to mobility and the costs associated with addressing these barriers, such as additional taxi fares.**

#### 4.11. Getting around

- 4.11.1. The proposed descriptor on getting around only addresses moving around outdoors. This does not take into account the significant mobility challenges that may be faced inside the home, especially when living alone.

*I have difficulties walking around, using stairs, (stairs are a nightmare, I can get down them with difficulty but getting up them without great pain is a no- no), and getting in and out of a chair (often a job and half!)*

- Person living with HIV

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<sup>5</sup> Characterised by the loss or redistribution of fat deposits, e.g. from the face, buttocks and the soles of the feet. Lipodystrophy is a side-effect of certain HIV medication. It can make it painful to sit down, or walk.

*Moving around indoors is often difficult for me because of my Peripheral Neuropathy and because of the amount of medication I take. I have ataxia and am otherwise often 'clumsy' and have poor co-ordination. Sometimes it's not noticeable to others because of the effort I am making to 'hold it together'. Other times it's dangerous and I can appear as if I am 'drunk'... The draft assessment looks at your ability to move around outdoors. Well, outdoors is a problem too, and sure I feel safer indoors- but feeling safer is not the same as being safer.*

- Person living with HIV

4.11.2. In addition, when considering moving around outdoors, the descriptor does not take into account factors that may stop the claimant going out, which are not solely related to physical inability to get around. For example, depression and anxiety, either in general or related to specific physical symptoms (such as incontinence), can affect the ability of someone living with HIV to move around outside without support

4.11.3. These barriers can be addressed through PIP, both in direct ways (paying for a taxi to allay fears of incontinence on longer journeys using public transport) and less direct means (helping pay for access to a support group or informal support networks, to improve mental and emotional well-being.)

*Trying to do the amount of exercise recommended not just on general health grounds, but in order to lessen the impact of muscle wasting and osteoporosis and as an antidote to depression, is an aspiration seldom achieved in full. The depression and fears about continence issues mean that I often get ready to leave the house and then am unable to do so. Or I get as far as the tube station and then have to return home aborting my journey. This limits and curtails my social life as well as my ability to do my own shopping.*

- Person living with HIV

## **Recommendations**

**The descriptor on getting around should consider mobility both inside and outside the home.**

**The descriptor around should consider a broad range of barriers to getting around, including the impact of mental health (including depression and anxiety) and physical impairment not limited to mobility (such as incontinence).**

## ***Key activities and costs which are missing from the assessment***

### **4.12. Social and leisure activities**

4.12.1. DWP has stated that PIP should support participation among people with disabilities and long-term conditions. However, there is absolutely no consideration of social or leisure activities in the assessment.

- 4.12.2. By contrast, DLA eligibility takes into account whether the claimant faced barriers to social activities, participating in their hobbies and attending places of worship, as a result of their health, and if extra support would increase their participation. As such PIP has even less of a focus on participation in the assessment as does DLA.

### **Recommendation**

**The PIP assessment should at least include the same amount of consideration of social and leisure activities as the previous DLA assessment.**

### **4.13. Utilities**

- 4.13.1. The most-cited use of DLA among people living with HIV is 'paying bills, e.g. electricity, water.'<sup>6</sup> Utilities are one of the most noticeable additional disability-related costs faced by people living with HIV, who need to ensure they keep their home well-heated, and may also face increased gas and water bills associated with needing to wash clothing and linen more often due to night sweats. However, it is currently not considered in any of the draft descriptors.

### **Recommendation**

**The additional burden of utilities costs on disabled people needs to be considered in the PIP assessment.**

## **6. New qualifying period**

- 6.1 NAT is concerned by the proposed new qualifying period for PIP, which at 6 months is twice as long as that used for DLA. We do not think that the reasons provided for this increase are sufficient to justify it.
- 6.2 The first reason given for the increase is that it will bring the qualifying period and prospective test in line with the Equality Act definition of disability, which notes that to be considered long term a condition
- has lasted at least 12 months; or
  - where the total period for which it lasts, from the time of the first onset, is likely to be at least 12 months; or
  - which is likely to last for the for the rest of the life of the person affected.

(Clearly the Equality Act definition is more complex than this, as conditions including HIV are always considered disabilities, without the need to prove the impact is 'substantial' or 'long term'.)

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<sup>6</sup> DBC survey

- 6.3 Aligning with this definition does not necessarily mean that the PIP qualifying period must be 6 months, followed by a 6 month prospective test. It would be equally valid to have a 3 month qualifying period, followed by a 9 month prospective test. The advantage of this arrangement would be those who are diagnosed with HIV late, at a point when they are already in urgent need of support, will not have to wait as long to access PIP.
- 6.4 The second reason given for increasing the qualifying period is to align it with Attendance Allowance (AA). It would be equally valid to align AA with the current DLA qualifying period, and the Government has provided no evidence on why the 6 month period is preferable for either or both benefits.

### **Recommendation**

**The qualifying period should remain at 3 months. If the Government wishes to align with the Equality Act definition of a disability which considers a 12 month period, the prospective test should be extended to 9 months to make up the difference. This is particularly relevant for those disabilities (including HIV) recognised by the Equality Act as conditions where the 'long term' test is not appropriate.**

## **7. Conclusion**

- 7.1 NAT strongly recommends reconsideration of the draft PIP assessment and significant alterations prior to testing.
- 7.2 The current approach of using functional descriptors as proxies is not an accurate measure of barriers to participation among people with disabilities including HIV. We recommend instead a more open-ended assessment which considers how both social factors and mental or physical impairments interact to create support needs and incur additional costs around key daily activities. The DBC alternative PIP assessment is a good starting point for the sorts of activities which should be considered.
- 7.3 Rather than a tick-box approach of descriptors which attract a range of point values, we recommend that the eligibility is based on whether the information provided by the claimant in response to open-ended questions, and their medical evidence, point to support needs and extra costs. Once eligibility is established, a scoring system may be applied to differentiate between the need for standard or enhanced rates of PIP.
- 7.4 While we recommend that DWP do not proceed with the assessment as currently drafted, if the functional descriptor approach is adopted it must be modified to more accurately measure participation and independence, as outlined in this submission.
- 7.5 The qualifying period should remain at 3 months. If the Government wishes to align the qualifying period and prospective test with the Equality Act definition of disability, this should be achieved by extending the prospective test to 9 months.

**NAT, June 2011**