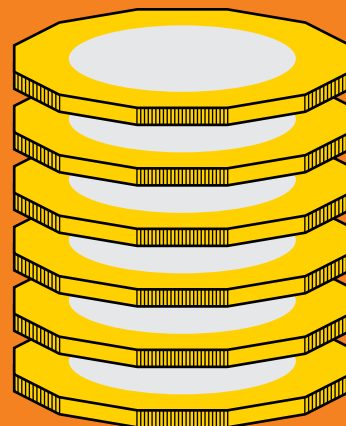
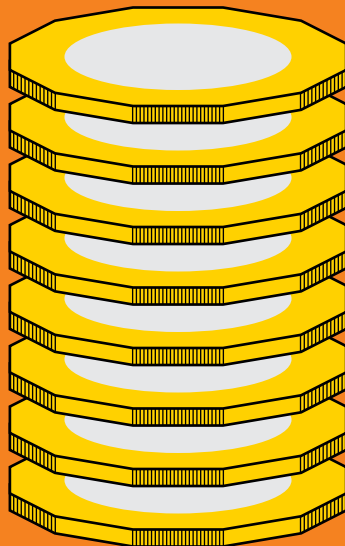
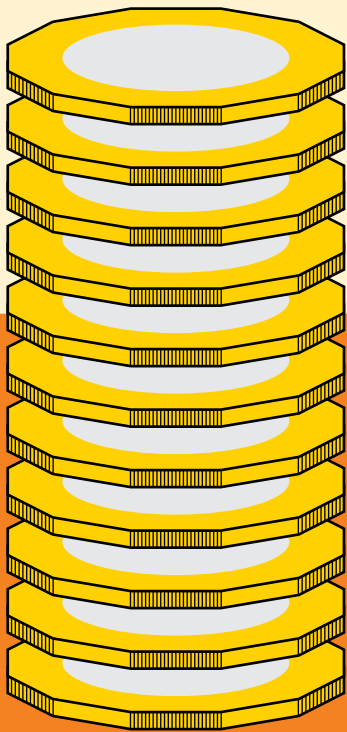


# PIP and HIV

How Personal Independence Payment is working for people living with HIV

JULY 2017



TRANSFORMING  
THE UK'S  
RESPONSE  
TO HIV



**NAT is the UK's leading charity dedicated to transforming society's response to HIV.**

**We provide fresh thinking, expert advice and practical resources.**

**We campaign for change.**

## **Our vision**

Our vision is a world in which people living with HIV are treated as equal citizens with respect, dignity and justice, are diagnosed early and receive the highest standards of care, and in which everyone knows how, and is able, to protect themselves and others from HIV infection

## **Our strategic goals**

All our work is focused on achieving five strategic goals:

- effective HIV prevention in order to halt the spread of HIV
- early diagnosis of HIV through ethical, accessible and appropriate testing
- equitable access to treatment, care and support for people living with HIV
- enhanced understanding of the facts about HIV and living with HIV in the UK
- eradication of HIV- related stigma and discrimination

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**Trust for London**

Tackling poverty and inequality

## Contents

Executive Summary	<b>2</b>
Section 1. HIV and extra-costs disability benefits	<b>5</b>
Section 2. Are people living with HIV who need PIP receiving it?	<b>10</b>
Section 3. A proxy for what? The PIP assessment	<b>14</b>
Section 4. How is the PIP process working for people living with HIV?	<b>21</b>
Conclusion	<b>27</b>

# EXECUTIVE SUMMARY

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## HIV and extra-costs disability benefits

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**The experience of life with HIV is diverse. A significant minority of people living with HIV in the UK will find their condition presents barriers to participation and independence. Personal Independence Payment (PIP) is a benefit which helps to pay for the extra costs of daily life with a long-term condition, thereby promoting independence.**

At the time that the Government abolished Disability Living Allowance (DLA), 10% of people living with HIV were in receipt of the benefit.

The changing face of HIV in the UK means that there are new groups of people living with HIV who may benefit from extra-costs support. A significant proportion of people living with HIV have one or more long-term conditions, in addition to HIV. People living with HIV can now expect to live a long life, but many will do so with a complex range of health needs and disabilities.

## Are people living with HIV who need PIP receiving it?

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DLA reassessments to date show that, compared to the overall population of people claiming DLA, people living with HIV are:

- less likely to be awarded PIP following reassessment
- less likely to receive an increase in their rate of benefit when moving from DLA to PIP
- more likely to receive a decrease in their rate of benefit when moving from DLA to PIP.

So far only around 1 in 8 people living with HIV on DLA at the time of the PIP roll-out have been reassessed for the new benefit.

As of October 2016, there were 1,282 people receiving PIP payments who had 'HIV/AIDS' listed as their main disabling condition. This represents 1.4% of people accessing HIV care in the UK.

61% of PIP claims currently in payment to people living with HIV are for new claims (not on DLA at the time of applying).

The appeal success rate for all PIP claims remains high, at 65%.

### A proxy for what? The PIP assessment

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The PIP descriptors are proxies for a basic existence and not for barriers to participation or the extra 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.

There have been two independent reviews of the PIP assessment, but the remit of both was strictly limited to implementation of the existing rules. The PIP criteria have not been subject to review since they were first developed.

The PIP assessment fails to account for the serious impact which HIV can have on participation and independence in the following ways:

- Even though PIP considers the impact of mental health on ability to get around outside of the house, the criteria define psychological distress in a very narrow and clinical way and set an extremely high threshold for support. NAT does not believe this accurately captures the risk of isolation due to HIV-related anxiety.
- The complex physical barriers to mobility experienced by people living with HIV do not map easily to the very narrow and specific PIP descriptors, which score according to the distance someone is able to walk.
- Differentiating between ability to walk 20 metres and ability to walk 50 metres in an inaccurate and unfair way of establishing who has the highest level of mobility support needs outside the home.
- Support with nutrition is one of the key reasons people living with HIV may need to access extra-costs disability support, but the PIP assessment only considers nutrition in terms of baseline physical capacity to prepare and eat food, not what this means for their independence.
- The importance of adherence to HIV medication to avoid deterioration of health is not reflected in the managing therapy descriptor, or the points which may be accrued by those who face barriers to basic self-management.

- The support needs around managing toilet needs and incontinence which are more likely to apply to people living with HIV are not considered by the PIP assessment.
- The PIP assessment has the potential to capture barriers to communication and social interaction experienced by people living with HIV-related cognitive impairment, but is much more limited in identifying barriers relating to mental health problems common among people living with HIV.

The current scoring threshold for PIP descriptors means that only people living with HIV who face the greatest challenges in these specific aspects of daily life or mobility will be eligible for support.

### How is the PIP process working for people living with HIV?

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The PIP assessment includes important safeguards for people who experience fluctuation in their health, a concern for many people living with HIV. However, the way these rules are applied through guidance may limit their usefulness.

Where people living with HIV have approached advice and support services for help with PIP claims, their advocacy and support needs have been significant, encompassing the whole PIP journey in many cases. This demand is likely to increase, as the vast majority of HIV DLA claims are yet to be re-assessed.

The stress which the face-to-face consultation causes people living with HIV indicates it is not currently a suitable process to gather evidence from people with complex support needs. This is especially pronounced in the case of stigmatised conditions like HIV.

Trust in the fairness of the PIP assessment is undermined by a perception that healthcare professionals working for assessment providers are trying to 'catch out' claimants, through their informal observations. People living with HIV and the advice workers who support them also question the accuracy of these observations as a source of evidence.

### Recommendations

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It is time to look again at Personal Independence Payment and whether the assessment design, criteria and current approach to scoring are suitable for a benefit designed to promote participation and independence.

The Personal Independence Payment Assessment Guide for assessment providers should also be reviewed, with attention to:

- Applying the reliability criteria in a way which increases the accuracy of assessments for people with fluctuating conditions.
- Collecting complete evidence first-time around, with appropriate weight to responses made by the claimant and their companion where applicable, to reduce to need for reconsideration and appeal.
- Using alternative sources of additional evidence to facilitate a greater proportion of paper-based assessments, for people with complex needs.
- How guidance on informal observations contributes to lack of trust in the fairness and accuracy of the assessment.
- Identifying positive actions to help reduce the anxiety and stress experienced by claimants, especially those with stigmatised conditions.

The Personal Independence Payment mobility criteria should be revised to:

- Remove the 20 metre threshold for the moving around descriptor, and replace with a 50 metre threshold.
- Create parity between psychological distress and sensory impairment, to the extent that these prevent someone from making a familiar journey without support.

In line with the functional approach taken by the Personal Independence Payment assessment, the impact of mental health-related barriers to participation daily living activities should not require a specific clinical diagnosis to be considered, where functional impact has been demonstrated.

The points thresholds for managing medication should reflect the seriousness of the health and disability impacts of failing to effectively self-manage treatments.

The impact on independence and participation of managing toilet needs when someone struggles to reach a toilet in time should be reflected in the relevant descriptor.

Advice and support services which support people living with HIV through the Personal Independence Payment assessment need to be appropriately funded. There should also be greater recognition of the resources which health, care and voluntary sector support professionals contribute to the success of assessments.

Services supporting people living with HIV who claim Disability Living Allowance should prepare themselves and their clients for Personal Independence Payment re-assessment, including financial planning support for those who may lose some or all of their support, without causing undue fear.

Clinicians providing evidence to support Personal Independence Payment assessments should familiarise themselves with the functional nature of the assessment and content of the descriptors, to ensure it is as relevant as possible to their patients' claims.

1

# HIV AND EXTRA-COSTS DISABILITY BENEFITS

**“We propose to replace Disability Living Allowance (DLA) with a new cash benefit – Personal Independence Payment – which will contribute to the extra costs of overcoming the barriers faced by disabled people to lead full and active lives.”<sup>1</sup>**

– Department for Work and Pensions, 2010

Experiences of living with HIV in the UK are diverse. Two-fifths of those diagnosed have their HIV picked up after they should already have been accessing treatment.<sup>2</sup> Others have lived with the virus for many years, diagnosed before modern treatments were available. Therefore, while someone who is diagnosed today and accesses today's highly effective treatment in good time should not expect to develop serious HIV-related health problems, there are many who live with the long-lasting health impacts of HIV infection, even though medication is now keeping the virus in their body completely under control.

Some in this group will need support with the extra costs associated with living with a disability. Personal Independence Payment (PIP), like its predecessor, Disability Living Allowance (DLA), offers fixed rates of financial support to help with meeting the extra costs of daily living and getting around.

This report looks at the extent to which PIP, introduced in 2013, is being accessed by people living with HIV and their experiences of applying for the new benefit.

## About PIP

In 2010 the Department for Work and Pensions (DWP) announced that DLA would be abolished and replaced with a new extra-costs benefit, PIP. DWP said that PIP would help disabled people to “exercise choice and control and lead independent lives”.<sup>3</sup>

Like DLA, PIP is a non-taxed benefit which can be paid to eligible claimants regardless of their income or whether they are in work. It also forms a ‘passport’ to other types of support (e.g. access to Motability vehicles and blue badge parking).

1 DWP. 2010. Public consultation. Disability Living Allowance reform.  
2 39% of new diagnoses in 2015 were among people with a CD4 count <350. Public Health England. Annual data tables 2016.  
<https://www.gov.uk/government/statistics/hiv-annual-data-tables>

3 DWP. Public consultation: Disability Living Allowance Reform. December 2010. p5.

## 1 HIV AND EXTRA-COSTS DISABILITY BENEFITS

The reasons DWP gave for the replacement of the old benefit<sup>4</sup> were:

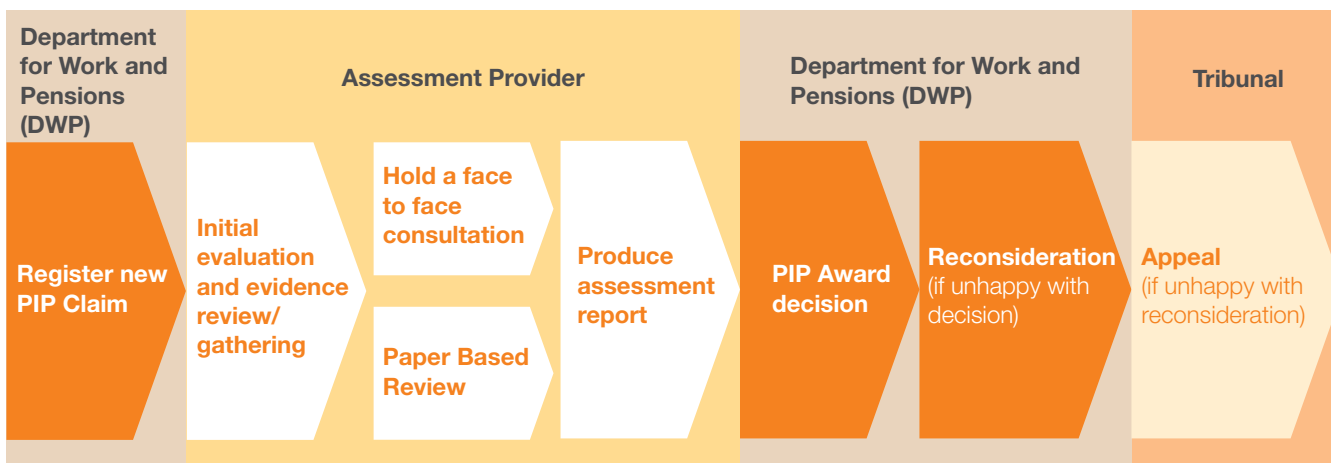
- The DLA case load had increased significantly over time.
- DLA had “become confusing and complex” as a benefit.
- DLA awards were not reviewed regularly to check the claimant was still eligible.
- DWP believed that DLA was perceived as an out-of-work benefit and that this discouraged disabled people from engaging in work.
- DLA was made automatically available to people with certain conditions.
- DWP wanted to better consider the impact of aids and adaptations when assessing claimants for extra-costs benefits.<sup>5</sup>

Like DLA, PIP has two components: daily living (replacing ‘care’ under DLA) and mobility. Each is paid at two possible rates: standard and enhanced. An individual can claim a single rate of either or some combination of care and mobility.

The assessment for the new benefit is similar in format to the Work Capability Assessment (WCA), introduced for Employment and Support Allowance (ESA) in 2008. It describes a range of activities which are considered proxies for support need – and therefore extra costs – in the areas of daily living (e.g. nutrition, washing and bathing) and mobility (getting around outside). Each activity is set out as a ‘descriptor’, with specific points allocated for a range of functional limitations. The more severe the limitation, the higher the points allocated. The points threshold must be reached for PIP to be awarded for each of the components (see section 3 for a more detailed description of the assessment).

Also like the WCA, the PIP assessment will in most cases be carried out in a face-to-face interview with a healthcare professional (HP) working for one of the two assessment providers (currently Atos and Capita). Based on this interview, the HP will provide evidence of functional limitation and make recommendations to a non-medically-trained DWP decision-maker, who decides whether or not PIP should be awarded. In some cases, a decision may be made on the application and evidence submitted by the claimant without the need for a face-to-face consultation. This is called a paper-based assessment.

### Stages in the Personal Independence Payment Assessment



4 DWP. Public consultation: Disability Living Allowance Reform. December 2010. p3.

5 DWP. 2010. Public consultation. Disability Living Allowance reform.



### Concerns around abolition of DLA for people living with HIV

The abolition of DLA in favour of PIP came with an explicit agenda to reduce Government spending on benefits for disabled people.<sup>6</sup> This, in combination with promises that the new benefit would be “targeted at those disabled people who face the greatest challenges” and that the number of indefinite awards would be dramatically reduced, created anxiety amongst many DLA claimants living with HIV that they would lose their extra-costs support.

People living with HIV are disproportionately affected by poverty. The Public Health England Positive Voices study, a national representative survey of people accessing HIV care in the UK, found that 15% of people living with HIV were falling behind with bills, compared to 6% of the general population. A third (33%) of people living with HIV said they sometimes skipped meals because of poverty – a further 17% did so often.<sup>7</sup>

There is also evidence to show that poverty has a detrimental impact on the success of HIV treatment and care. The ASTRA study of 3,000 people accessing HIV care in England in 2011/12 found variation in the extent to which people were benefitting from HIV treatment and care. One of the factors associated with not achieving viral suppression (the goal of HIV treatment) was financial hardship.<sup>8</sup> The REACH study, which looked at attendance and engagement with HIV treatment and care services in London in 2014/15, found that not always having enough money for basic needs was a common problem for regular clinic attenders (51%) – but even more so for irregular attenders (65%) and non-attenders (66%). Likewise, 14% of regular attenders sometimes went hungry, compared to 28% of irregular attenders and 24% of non-

attenders.<sup>9</sup> There is a clear association between not having enough money and not benefitting fully from the treatment and care which the NHS provides.

DLA and PIP are extra-costs supports, not income-replacement benefits, so are not intended to directly address the impacts of poverty. Neither are means-tested benefits, acknowledging that disability creates extra costs for everyone. But it should not be forgotten that the independence promoted by DLA has frequently taken the form of filling a gap in an otherwise very low income, allowing the purchase of basic needs like healthy food and transportation which may not be possible even when someone is receiving income-replacement help in the form of, for example, Employment and Support Allowance (ESA).

One of the main reasons given for replacing DLA with PIP was that two-thirds of DLA claimants had an indefinite award, meaning it would not be subject to review unless the claimant reported a change in their circumstances.<sup>10</sup> However, the introduction of PIP is not the first time that people living with HIV have faced a mass review of their eligibility for DLA.

In 2006 the Government announced a review of ‘special rules’ DLA claims, which were those awarded to people on the basis of a ‘progressive condition where death can usually be expected within six months’. This allowed access to the higher rate of the DLA care component, without the need to satisfy the usual three-month qualifying period, for an indefinite period. Under the review, people who no longer met the definition for special rules would have their claim reassessed under regular DLA rules – meaning a reduction, or total loss in the benefit, for some.

The review was a cause of significant anxiety for some people living with HIV who had been receiving DLA for many years on the basis of a special rules claim, based on an assessment made prior to availability of modern treatment. Some lost access to the benefit altogether, but others continued to receive DLA at the same or lower rates based on their current care and mobility support needs,

6 Over £1 billion in savings identified for the period covered 2010-2011 to 2014-2015. This was subsequently reduced as the timetable for PIP implementation was adjusted. NAO. Personal Independence Payment: early progress. HC 1070 SESSION 2013-14 27 FEBRUARY 2014. <https://www.nao.org.uk/report/personal-independence-payments-pip-2/>

7 Meaghan Kall on behalf of the Positive Voices study group. Personal communication to NAT, 2016. Positive Voices surveyed a representative 1% sample of the population of people attending HIV clinics in 2014.

8 Burch et al. ‘Socio-economic factors and virological suppression among people diagnosed with HIV in the United Kingdom: results from the ASTRA study.’ *Journal of the International AIDS Society*, 2014; 17(4 Supp 3): 19533.

9 Peabody, R. ‘Multiple social and health factors associated with irregular attendance at London HIV clinics’. 22 April 2016. <http://www.aidsmap.com/Multiple-social-and-health-factors-associated-with-irregular-attendance-at-London-HIV-clinics/page/3049649/>

10 DWP. Public consultation: Disability Living Allowance Reform. December 2010

including on long-term or indefinite awards. For some in this group – and others with indefinite awards dating even further back – the introduction of a completely new benefit and assessment has been extremely stressful.

“The change from DLA to PIP which I will get a review regarding in 2015 has meant I am constantly worrying, I cannot support myself without this benefit and knowing how difficult they have made the new rules it’s a constant worry.”

– respondent to survey by Counterpoint Alliance on the impact of welfare reform on people living with HIV in England, 2014.

### PIP and the changing face of HIV in the UK

People who have been living with HIV for many years and have claimed DLA, are a key group whom we should expect will benefit from PIP. The need for support with the extra costs of living with a disability is not limited to these long-term survivors, however.

Even as HIV treatments continue to improve in terms of effectiveness, lack of side-effects and ease of adherence, not everyone newly diagnosed today will experience their full benefit. There is still a significant minority of people newly diagnosed with HIV once they have already become ill – some with life-long impairments. In 2015, 39% of people newly diagnosed with HIV were diagnosed ‘late’, indicating they should already have been on treatment. Late HIV diagnosis remains clearly linked to increased rates of illness, hospital admission and mortality, as well as reduced life expectancy.<sup>11</sup> Late diagnosis leaves an individual ten times more likely to die within a year of diagnosis.<sup>12</sup>

HIV is a complex condition which, when not controlled through highly effective antiretroviral treatment, can affect not only the immune system but a wide range of other body systems, including the respiratory, gastrointestinal and nervous systems. People living with HIV therefore present with a wide range of needs which are relevant to extra-costs support, with physical, mental and cognitive health dimensions.

11 May, M et al. ‘Impact of late diagnosis and treatment of life expectancy in people with HIV-1: UK Collaborative HIV Cohort (UK CHIC) Study’, 2011, *BMJ*: 343:d606

12 Stockle, M et al. ‘Morbidity and mortality in HIV infection,’ *Internist (Berl)*; Antinori, A et al., 2011 ‘Late presentation of HIV infection: a consensus definition.’ *HIV Medicine*, 2012, 12 (1): 61-64.

Co-morbidity (living with multiple long-term conditions) is more common among people living with HIV than the general population. The Positive Voices study found that two-thirds of people living with HIV in the UK have at least one other condition, in addition to HIV, and 38% have more than one additional condition.<sup>13</sup> The proportion living with an additional condition increases to more than three-quarters among those aged 50 or over.<sup>14</sup> The population of people living with HIV is an ageing one. Over the past decade, the median age of people accessing HIV care has increased from 39 to 45.<sup>15</sup> A third (34%) are aged 50 or over and by 2028 this proportion will be 54%.<sup>16</sup>

Finally, a key sub-population of people most-affected by HIV in the UK are those born in sub-Saharan Africa, a large proportion of whom arrived as asylum seekers and migrants in the mid-2000s. Asylum seeking and migration from these countries of high HIV prevalence has reduced in recent years but the population who arrived in the previous decade have gradually achieved stable residency status in the UK as asylum claims were resolved and migration status was regularised.<sup>17</sup> However, black African people living in the UK are still disproportionately affected by HIV. In 2015, over half of people with black African ethnicity diagnosed with HIV were diagnosed late, compared to 39% for the overall newly-diagnosed population and 30% of newly-diagnosed gay and bisexual men. This suggests that a proportion of black African men and women living with HIV will have health-related support needs, even if they have been recently diagnosed. NAT’s research into the needs of black African people living with HIV in the UK has found that there are likely to be more individuals eligible for disability benefits than are

13 Kall M et al ‘Self-reported prevalence of co-morbidities and use of non-HIV related medications among people living with HIV in England and Wales: results from the Positive Voices survey’ 15th European AIDS Conference. Barcelona, Spain; October 21-24 2015.

14 Kall M et al ‘Self-reported prevalence of co-morbidities and use of non-HIV related medications among people living with HIV in England and Wales: results from the Positive Voices survey’ 15th European AIDS Conference. Barcelona, Spain; October 21-24 2015.

15 Public Health England. HIV in the UK: 2016 report. [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/602942/HIV\\_in\\_the\\_UK\\_report.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/602942/HIV_in_the_UK_report.pdf)

16 Public Health England. ‘Table 10: Persons seen for HIV care by country and PHE region of residence and demographic group: 2015’. National HIV Surveillance data tables. 2016.

<https://www.gov.uk/government/statistics/hiv-annual-data-tables>; King’s Fund. 2017. The future of HIV services in England. <https://www.kingsfund.org.uk/projects/future-hiv-services-england>

17 Public Health England. HIV in the UK: 2016 report. [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/602942/HIV\\_in\\_the\\_UK\\_report.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/602942/HIV_in_the_UK_report.pdf)

## 1 HIV AND EXTRA-COSTS DISABILITY BENEFITS

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currently accessing them.<sup>18</sup> PIP therefore presents an opportunity for support for a group of people living with HIV who may not have benefitted previously from DLA but may have substantial support needs.

### NAT's research

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In response to the concerns and potential opportunities surrounding the new benefit, NAT researched the PIP experience so far of people living with HIV.

This report draws on official Government statistics about the number of people living with HIV who have been awarded PIP, looking both at those who have claimed an extra-costs benefit for the first time and those who have been reassessed from DLA.

We have gathered the experiences of people living with HIV via support services and welfare advisors, as well as directly from individuals.

We also analysed the PIP assessment and rules in light of what we know about the common impairments experienced by people living with HIV and the support needs they may have, drawing on our earlier research into how DLA was used by people living with HIV.

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<sup>18</sup> NAT. 2014. HIV and black African communities living in the UK. <http://www.nat.org.uk/sites/default/files/publications/NAT-African-Communities-Report-June-2014-FINAL.pdf>

# 2

## ARE PEOPLE LIVING WITH HIV WHO NEED PIP RECEIVING IT?

The limited roll-out of PIP so far indicates that people living with HIV are less likely to receive PIP than the overall population of DLA claimants. Those who are successful are less likely to receive an increase in their rate of benefit when moving from DLA to PIP, and more likely to receive a decrease in their rate of benefit when moving from DLA to PIP, than the overall DLA population.

The reassessment process is ongoing, so we do not yet know how many people living with HIV will be in receipt of PIP by the end of the roll-out. Nor can we draw a full comparison between the proportion of people accessing PIP who were accessing DLA at the time the benefit was abolished, and those who are now accessing PIP. However, official statistics to date indicate that people living with HIV are not as likely to be successful in a DLA re-assessment as those with other conditions.

PIP opened to new claims from April 2013

Certain DLA claimants were re-assessed for PIP from September 2013

From July 2015, people with long-term or indefinite DLA claims started to be contacted about the need to re-apply for PIP

DWP currently expects re-assessments to be completed by the end of 2018

### Number of people living with HIV receiving PIP

As of October 2016, there were 1,282 people receiving PIP payments who had 'HIV/AIDS' listed as their main disabling condition.<sup>19</sup> This represents 1.4% of people accessing HIV care in the UK.<sup>20</sup>

There may also be cases where the claimant is living with HIV but this is not listed as their main disabling condition. For simplicity, though, the remainder of

19 'HIV/AIDS' is the category used by the DWP official PIP statistics. PIP claims are classified by main disabling condition as part of the assessment process. For the remainder of this report, 'HIV' will be used.

20 The most recent available published statistics show that 88,769 people living with HIV were accessing HIV care in December 2015. This will have increased in the time to September 2016 and will therefore affect the calculation of the proportion of people accessing HIV care who are in receipt of PIP. However, assuming the number of people in care increases by a similar number as previous years, the proportion would remain between 1 and 1.5% of this population.

## 2 ARE PEOPLE LIVING WITH HIV WHO NEED PIP RECEIVING IT?

this report use ‘people living with HIV’ when referring to those who have listed HIV as their main disabling condition.

The total PIP caseload across the UK is 1.09 million claims in payment (HIV claims make up 0.1% of this total). To put the number of HIV-related claims in context, a similar number of claims are in payment for main disabling conditions including motor neurone disease, cardiomyopathy and ulcerative colitis.

To compare with DLA, at the time that the PIP roll-out commenced, there were 7,920 people receiving DLA payments who had ‘AIDS’ listed as their main disabling condition.<sup>21</sup> This represented 10.3% of people accessing HIV care at the time.<sup>22</sup> The total DLA caseload at this point was 2.81 million (HIV claims were 0.3% of the total).

A significant proportion of this 7,920 are still in receipt of DLA – 6,820 as of May 2016, the last DLA statistics published. In other words, only around 1,000 DLA cases for people living with HIV have been reassessed (or otherwise closed, for example if someone decided not to go through with re-assessment). The vast majority of people living with HIV who receive DLA are still waiting for re-assessment.<sup>23</sup>

At this stage in the PIP roll-out, we would have expected to have a much clearer indication of trends in PIP claims and DLA reassessment outcomes for

people living with HIV. This reflects overall delays in the roll-out of PIP.<sup>24</sup> However, in the next two sections we will consider what observations and conclusions can be drawn from those claims which have so far been assessed.

### Outcomes for new claims (not previously on DLA)

Before the roll-out of reassessments for people with long-term and indefinite DLA awards commenced in July 2015, the majority of PIP assessments were for people who were not already receiving an extra-costs benefit (normally called ‘new claims’).

As of October 2016 there were 780 new claims awarded to people living with HIV.<sup>25</sup> This is 61% of all PIP awards currently in payment to people living with HIV. The rates of PIP awarded are detailed in Table 1.

The largest proportion (27%) of new claims awarded to people living with HIV were for the enhanced rates of both the Daily Living and the Mobility components, indicating a high level of support need.

DWP is unable to provide condition-specific statistics relating to the success rate for new PIP claims (the proportion of people who receive an award at the end of their assessment), so we cannot say what proportion of new claims for people living with HIV are successful. Overall, 43% of new PIP claims are successful.<sup>27</sup>

**Table 1. New PIP claim awards – HIV<sup>26</sup>**

		PIP Mobility		
		Enhanced	Standard	Nil
PIP Daily Living	Enhanced	210	110	100
	Standard	30	100	200
	Nil	#	30	—

(# indicates that there were fewer than 5 cases)

21 DWP official statistics from May 2013 accessed from <https://www.gov.uk/guidance/dwp-benefit-statistics-dissemination-tools>. ‘AIDS’ was the category used by the DWP official DLA statistics. For the remainder of this report, ‘HIV’ will be used.  
 22 At the end of 2012 there were 77,463 people accessing HIV care.  
 23 DWP official statistics accessed from <https://www.gov.uk/guidance/dwp-benefit-statistics-dissemination-tools>

24 NAO. Personal Independence Payment: early progress. HC 1070 SESSION 2013-14 27 FEBRUARY 2014. <https://www.nao.org.uk/report/personal-independence-payments-pip-2/>  
 25 Data provided by DWP following a Freedom of Information Request.  
 26 Data provided by DWP following a Freedom of Information Request.  
 27 Not including claims made through the special rules for terminal illness, almost all of which are successful.

## 2 ARE PEOPLE LIVING WITH HIV WHO NEED PIP RECEIVING IT?

### Outcomes for DLA re-assessments

Up to October 2016, 1,000 people living with HIV had been re-assessed from DLA under the new PIP rules. 63% were found eligible for PIP and 30% were disallowed following referral for assessment.<sup>28</sup> A further 5% had their claim disallowed prior to being referred for assessment – this means that DWP decision-makers found that they did not meet the basic criteria for a PIP claim. 1% withdrew their claim before appeal.<sup>29</sup>

**Table 2. DLA to PIP Reassessments – HIV**

PIP Reassessment Outcome							
Main Disabling Condition	Award Increased	Award Unchanged	Award Decreased	Disallowed post referral to the AP	Disallowed pre referral to the AP	Withdrawn	Total
AIDS*	21%	15%	27%	30%	5%	1%	1,000
All Conditions	40%	12%	23%	21%	4%	1%	526,500

\*AIDS' was the term used in the official DLA statistics

To date, then, people living with HIV are less likely to be successfully re-assessed for PIP than the overall population of DLA claimants, 73% of whom have been awarded PIP at reassessment.<sup>30</sup> People living with HIV are more likely to be refused PIP, less likely to have had their rate of award increased,<sup>31</sup> and more likely to have had it decreased, than the overall DLA population.

Of people living with HIV who were found eligible for PIP at re-assessment, 43%<sup>32</sup> were awarded a lower rate of support than they had been receiving under DLA (compared to 30% of successful claims across

all conditions<sup>33</sup>). 33% of people living with HIV received a higher rate of support than they had on DLA (compared to 53% of successful claims across all conditions).<sup>34</sup>

Of DLA claimants with HIV who were awarded PIP on re-assessment, 22% have been awarded the enhanced rate of both components (a similar proportion to those with new claims – 27%).

It should be kept in mind that in order for a DLA claimant to be re-assessed for PIP, they must respond to an 'invitation' from DWP and apply in the same way as a new claim. Until the DLA-PIP reassessment process is complete, we have no way knowing how many of the 6,820 people living with HIV who were receiving DLA in May 2016 have since been invited to claim, but did not go through with the process.

28 The majority of this group are refused for failing to score enough points on assessment, but will also include those disallowed PIP because they did not attend an assessment appointment without good reason.

29 DWP. PIP Official statistics for the period 8th April 2013 to 31st October 2016. 14 December 2016. Table 8D: Summary of DLA to PIP Reassessment Outcomes: Breakdown by Main Disabling Condition

30 DWP. Personal Independence Payment: Official Statistics Quarterly Data to October 2016 Published: 14 December 2016. [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/577399/PIP-statistics-to-october-2016.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/577399/PIP-statistics-to-october-2016.pdf)

31 Defined by DWP as an award of higher monetary value.

32 27% of total HIV reassessment claims, 43% of successful reassessment claims

33 23% of total reassessment claims, 30% of successful reassessment claims

34 21% of total HIV reassessment claims, 33% of successful reassessment claims

## 2 ARE PEOPLE LIVING WITH HIV WHO NEED PIP RECEIVING IT?

**Table 3. DLA to PIP re-assessments – rates of award – HIV**

		PIP Mobility		
		Enhanced	Standard	Nil
PIP Daily Living	Enhanced	220	70	40
	Standard	50	100	110
	Nil	#	20	—

(# indicates that there were fewer than 5 cases)

### Reconsideration and appeals

If a claimant disagrees with the outcome of the PIP claim, they may seek a reconsideration by a DWP decision-maker.<sup>35</sup> If they disagree with the outcome of the reconsideration, they may seek an appeal at tribunal.

Overall, PIP appeal statistics for 2016/17 show that 65% of appeals in each of the first three quarters of the year overturned the DWP decision.<sup>36, 37</sup> We were not able to get HIV-specific statistics relating to reconsideration or appeal.

By contrast, only 22% of DWP reconsiderations for DLA reassessment claims and 15% of reconsiderations for new claims resulted in an alteration to the original decision.

Why are appeals at tribunal so much more likely to be successful than reconsiderations? The number of cases which have gone through reconsideration since PIP was implemented (299,990) is higher than those which go to appeal (107,645). It may be that cases which are taken to tribunal are self-selected to have greater merit; but at the same time, many cases with significant merit will not go to appeal. The tribunal process can be intimidating and people who are not being supported by an advocate or organisation with welfare expertise may be reluctant to attempt it alone. It should also be remembered all appeal cases found in favour of the claimant have previously been upheld by the DWP reconsideration process. It seems plausible that if a greater number

of PIP claims upheld at reconsideration went to appeal, a greater number of PIP claims would be overturned by tribunal than is currently the case.

### CASE STUDY 1

#### **An HIV support service in the East Midlands supported a client with a reconsideration process:**

*“My client was initially granted enhanced rate care and standard rate mobility of PIP. He was not happy with this decision as he previously had been granted higher rate mobility for an indefinite period. He was unhappy that the assessor had visited and witnessed the room that he lives in as well as the fact that he was in bed for the entire assessment, but she had found him to not have a high mobility need.*

*The client requested a reconsideration which I supported him to write. The DWP turned this down. It was at this point that I suggested to the client to collect additional evidence. He was able to give a supporting letter written by his HIV specialist nurse when he sent his evidence off to the appeal tribunal. Once the DWP received the new supporting letter, they overturned the decision they made and consequently awarded my client enhanced rate PIP for his mobility. This was despite the fact that they already had supporting evidence for his conditions from specialist consultants. The tribunal appeal was cancelled. My client was happy that the decision was overturned.”*

<sup>35</sup> Called ‘mandatory reconsideration’ – the mandatory refers to this being a mandatory step prior to seeking appeal at tribunal, but as the term can be misleading ‘reconsideration’ is being used instead.

<sup>36</sup> Quarter 4 statistics for 2016/17 were not available at the time of writing.

<sup>37</sup> Ministry of Justice. Official statistics. Tribunals and gender recognition certificate statistics quarterly: October to December 2016. Published 9 March 2017.

# 3

## A PROXY FOR WHAT? THE PIP ASSESSMENT

**The PIP descriptors are proxies for a basic existence and not for barriers to participation or the extra 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.**

**There have been two independent reviews of the PIP assessment, but the remit of both was strictly limited to implementation of the existing rules. The PIP criteria have not been subject to review since they were first developed.**

When consulting on plans to replace DLA with PIP, the DWP promised that the new benefit:

“...will continue to take account of the social model of disability. The assessment will be objective, reflect the impact of the barriers disabled people may experience, and make sure they are treated as individuals.”<sup>38</sup>

Despite this commitment, the PIP assessment takes the same ‘tick-box’ approach which has been widely

criticised in relation to Employment and Support Allowance for failing to accurately capture the complexity of health conditions and barriers faced by individuals. The DWP describes the descriptors chosen to make up the assessment as “proxies for an individual’s ability to participate in everyday life”.<sup>39</sup> Participation is defined in the assessment as “involvement in life situations.”<sup>40</sup>

However, the activities which form the basis of the descriptors are strictly functional in nature (e.g. taking nutrition, moving around). While these concerns are relevant to participation, the activities chosen and the criteria for allocating points are much closer to a medical model of disability than a social one. These necessarily make the focus of the assessment severity of impairment, rather than individual barriers to participation, in a social context.

Indeed, the focus on severity of impairment is much more strongly supportive of DWP’s other stated goals for PIP, as compared to DLA, which is that it would be targeted at those with the “greatest need”. This clearly implies that some people who have genuine barriers to participation may still not meet the threshold for PIP.

38 DWP. Public consultation: Disability Living Allowance Reform. December 2010. p11.

39 Technical note to the initial draft PIP assessment. DWP consultation document May 2011.

40 DWP. PIP Assessment Guide. October 2016.



### 3 A PROXY FOR WHAT? THE PIP ASSESSMENT

Throughout the development and rollout of PIP, NAT has questioned the appropriateness of the proxies – and the assessment overall – for establishing the real barriers to participation experienced by people living with HIV.

There have been two independent reviews of the PIP assessment, but the remit of both was strictly limited to implementation of the existing rules. The PIP criteria have not been subject to review since they were first developed.

The following section will illustrate the gaps between what the PIP assessment promises to capture and the reality, looking specifically at how key activity descriptors apply to the support needs of people living with HIV.

As some activity descriptors are more directly relevant to the needs of people living with HIV than others, only a selection of key descriptors are discussed in detail below.

#### Getting about outside the home

The way in which PIP assesses barriers to mobility has been one of the major areas of controversy compared to the previous DLA assessment. There are two descriptors dealing with issues around mobility – both exclusively relating to mobility outside of the home.

The first, ‘planning and following a journey’, is explicitly designed to capture mobility issues relating to mental health problems, cognitive and sensory impairment. The second, ‘moving around’, is intended to capture the impact of physical impairment on mobility. In order to receive the PIP mobility component, the claimant must score at least eight points (standard rate) or 12 points (enhanced rate) across one or both of the descriptors. By contrast, for the daily living component of PIP the eight or 12 points may be accrued across 10 separate activities.

Planning and following a journey has the potential to pick up some of the important mental health-related barriers to participation experienced by people living with HIV. People living with HIV are disproportionately

#### The daily living activities

- preparing food
- eating and drinking
- managing your treatments
- washing and bathing
- managing toilet needs or incontinence
- dressing and undressing
- communicating verbally
- reading and understanding written information
- mixing with others
- making decisions about money

#### The mobility activities

- planning and following a journey
- moving around

affected by anxiety.<sup>41</sup> The ongoing problem of HIV stigma within our society means that for some people this anxiety is tied up with fear of the reactions of others to their HIV positive status. The planning and following a journey descriptor addresses this impact of anxiety, which is welcome. However, as with other PIP descriptors, the way this descriptor is applied in practice limits its usefulness for assessing people living with HIV.

Firstly, the descriptor sets a very high concept threshold for the point at which the impact of anxiety around leaving the house will be considered. The terminology used is ‘overwhelming psychological distress’.

The descriptor also sets a very challenging points threshold, even for those who experience overwhelming psychological distress, to be found eligible for the PIP mobility component. For example, someone who “needs prompting to be able to undertake any journey to avoid overwhelming psychological distress” will only accrue four points for this descriptor. Prompting means “reminding, encouraging or explaining by another person”. In the PIP assessment guide for HPs, DWP illustrates this

41 BPS/BHIVA/MEDFASH. Standards for Psychological Support for People Living with HIV. <http://www.bps.org.uk/standards-psychological-support-adults-living-hiv>

descriptor with the example of someone who “is actively suicidal or is at substantial risk of exhibiting violent behaviour and who needs ‘prompting’ not to harm themselves or others when undertaking a journey”. Even then, “there must be good evidence that the person is a high suicide risk”.<sup>42</sup>

In an example which has parallels for many people living with HIV who experience anxiety, someone who is only able to make a single daily journey independently without the need for prompting or assistance (such as to a child’s school or to the shop) will not be eligible for any points – even if there are unable to make any other journey independently. This does not meet NAT’s understanding of participation and social inclusion.

The Upper Tribunal, which hears PIP appeals, has interpreted the PIP rules in a way which takes better account of the impact of overwhelming psychological distress. Their position has been that someone who can’t get around without assistance from someone else because of the impact of this distress, should be scored as highly as someone who can’t get around without an assistance dog or sensory aid. However, the Government has recently responded by passing regulations to reverse this more generous interpretation.<sup>43</sup>

Thirdly, the guidance to assessors around the use of

this descriptor narrowly defines overwhelming psychological distress as “distress related to an enduring mental health condition or intellectual or cognitive impairment which results in a severe anxiety state in which the symptoms are so severe that the person is unable to function.”<sup>44</sup> This is something which not all people living with HIV will be able to prove with necessary medical evidence, even if they experience the practical impact of this level of distress.

This narrow interpretation of psychological distress excludes any possible consideration of the interaction between physical health impacts (e.g. incontinence) and psychological impacts (e.g. anxiety fuelled by experiences of HIV stigma), which mean that someone living with HIV may not be able to leave the house without prompting or assistance from others.

This combination of flaws in how the descriptor is applied means that people living with HIV who face genuine mobility needs, arising from HIV-related anxiety, will not be getting the support they need.

The second mobility-related descriptor, moving around, is intended to focus on any physical barriers to standing up and walking particular distances.

HIV may lead to walking difficulties for a number of reasons. These include muscle weakness, problems with the central or peripheral nervous system and breathing difficulties.<sup>45</sup> Pain, including peripheral neuropathy (nerve pain), joint pain and visceral pain can also affect ability to walk.

Welfare rights advisors with HIV expertise told us that the previous DLA assessment allowed for these factors to be considered, as the criteria considered whether someone was “virtually unable to walk”, taking into account: “the distance they can walk; the speed of their walking; the length of time it takes; and the manner of their walking.”<sup>46</sup> Being found virtually unable to walk would qualify the claimant for the higher rate of mobility support under DLA (conferring access to the Motability scheme for adapted cars, and/or a higher rate of payment). In practice, inability to walk more than 50 metres would count as being virtually unable to walk. Equally, if

#### CASE STUDY 2

##### **HIV support worker based in London whose client was awarded enhanced rate mobility:**

*“The outcome has had a positive effect on the client as he is now able to claim a taxi card. He is also able to use the money to attend more social activities which is resulting in a positive impact to his mental wellbeing. The client also feels that this is having a positive impact on his ability to be more independent. The client is now able to attend our HIV organisation regularly and gain further professional and social support.”*

42 DWP. PIP Assessment Guide. October 2016. p127

43 Social Security: Written statement – HCWS495  
<http://www.parliament.uk/business/publications/written-questions-answers-statements/written-statement/Commons/2017-02-23/HCWS495/>

44 DWP. PIP Assessment Guide. October 2016. p126

45 NAM aidsmap. HIV treatments directory: Walking difficulties.  
<http://www.aidsmap.com/Walking-difficulties/page/1733049/>

46 Disability Rights UK. 2017. Disability Living Allowance. Factsheet F23. 6 April 2017.  
<https://www.disabilityrightsuk.org/disability-living-allowance-dla>

### 3 A PROXY FOR WHAT? THE PIP ASSESSMENT

someone could walk further than 50 metres but only with significant pain or discomfort, they would also be considered virtually unable to walk.

The moving around descriptor under PIP considers ability to stand and move over a range of very precise distances, each of which attracts a certain number of points. It also explicitly takes into account whether someone can walk with the help of an aid (e.g. walking stick).

**Table 4. Mobility Descriptor 2. Moving Around.**

<b>2. Moving around</b>	a. Can stand and then move more than 200 metres, either aided or unaided	0
	b. Can stand and then move more than 50 metres but no more than 200 metres, either aided or unaided.	4
	c. Can stand and then move unaided more than 20 metres but no more than 50 metres.	8
	d. Can stand and then move using an aid or appliance more than 20 metres but no more than 50 metres.	10
	e. Can stand and then move more than 1 metre but no more than 20 metres, either aided or unaided.	12

The introduction of a 20 metre threshold for eligibility for the enhanced rate or PIP (compared to 50 metres under DLA) has been one of the common areas of concern for the new assessment across disabilities and long-term condition areas. A judicial review was brought regarding what some disabled people (and organisations including NAT) considered to be insufficient consultation on the move from a 50 to 20 metre threshold in order to access enhanced rate mobility (and therefore the Motability scheme and other key passported benefits).<sup>47</sup> NAT does not believe that such a fine distinction between capacity to walk 20 metres and 50 metres is fair, nor do we think it is possible to meaningfully evidence this difference, especially given the multifactorial barriers to walking which are experienced by people living with HIV.

HIV specialist welfare rights advisors and support services told us that the approach to mobility taken by the PIP assessment is a barrier to appropriate support for people living with HIV who have previously accessed motability support.

#### CASE STUDY 3

**An HIV case worker in the West Midlands supported a client with her re-assessment from DLA to PIP. The client was in receipt of higher rate mobility and middle rate care DLA, due to her HIV and ME-related support needs. This allowed her to use the Motability scheme for adapted vehicles, which is open to those on higher rate DLA mobility and enhanced rate PIP mobility.**

**As she was able to mobilise more than 50m, she was found eligible for only the standard rate of PIP mobility and lost access to Motability. The case worker told NAT her client “was devastated as she then lost her mobility car – i.e., her freedom.”**

<sup>47</sup> The Queen on the application of Steven Sumpter and the Secretary of State for Work and Pensions [2014] EWHC 2434 (Admin) Case No: CO/3843/2013.  
<https://www.disabilityrightsuk.org/sumpter>

#### CASE STUDY 4

**A London HIV organisation supported a client with HIV-related neuropathy and back pain in his re-assessment for PIP. As his needs had not changed, they were expecting that he would be eligible for higher rates of both components, as was the case with his DLA claim. The client had a lot of relevant evidence from his clinical team. He attended a face-to-face interview with an HP but reported to his support worker that “they did not hear everything he had to say”.**

**The client was awarded PIP Daily Living component at the standard rate and no mobility support. He is seeking reconsideration of the decision. His support workers is concerned that if the client is unsuccessful in this, “he will lose his Motability car, which will result him being very isolated. This will have an impact on his physical and mental health.”**

#### Nutrition

The PIP Daily Living criteria include two descriptors relating to nutrition. A survey of disability benefits recipients in 2010, when the PIP assessment was still being drafted, found that more than half of DLA claimants with HIV said that buying food was one of the top three uses of their extra-costs support.<sup>48</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. People living with HIV need to consume enough appropriate food in order for their medication to be effective. At the same time, that essential medication may trigger nausea and gastro-intestinal problems.

The quality and quantity of food available to people living with HIV is important, and dietary supplements may also be necessary if immune function has not fully recovered. Both add significant additional costs, especially for people on low incomes or reliant on out of work benefits. In 2014, the then-chair of the British HIV Association (BHIVA), reported that HIV

consultants were prescribing food supplements to some of their patients who were not consuming enough as a result of poverty.<sup>49</sup>

Using extra costs benefits to pay for these HIV-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. Unfortunately, the PIP criteria do not reflect this benefit as clearly as was the case for DLA.

The first relevant descriptor, preparing food, considers an individual’s ability to make meals and snacks without supervision or assistance. Someone who ‘needs prompting to be able to either prepare or cook a simple meal’ on the majority of days would only accrue two points under the assessment, as would someone who cannot safely use a conventional cooker (but can use a microwave to cook or heat food). Either of these descriptors could apply, for example, to someone living HIV-related cognitive impairment, and both point to a potential risk to health and need for extra support. But even if both applied simultaneously the PIP rules mean that the claimant would only be scored two points – far below the threshold of eight needed to be awarded daily living support.

#### CASE STUDY 5

**A man in his 40s living with HIV in receipt of DLA explained his challenges around nutrition:**

*“I can prepare and cook a simple meal but this takes a lot of effort. I live alone and sometimes don’t bother. When I am depressed I also fail to eat a meal. Friends rally around. I have a specially adapted cooker and have to use grab sticks etc. I have burnt myself a lot and haven’t known it as I have no feeling in the bottom half of my body.”*

48 Analysis of anonymous online survey data collected for the DBC report *Benefiting Disabled People?* (March 2011) <https://disabilitybenefitsconsortium.wordpress.com/2011/03/23/benefiting-disabled-people/>

49 ‘Thousands of HIV patients go hungry as benefits cuts hit.’ *The Independent*. 23 February 2014. <http://www.independent.co.uk/life-style/health-and-families/health-news/exclusive-thousands-of-hiv-patients-go-hungry-as-benefit-cuts-hit-9146888.html>

### 3 A PROXY FOR WHAT? THE PIP ASSESSMENT

The second nutrition-related descriptor is taking nutrition, focussing on “a person’s ability to be nourished, either by cutting food into pieces, conveying it to the mouth and chewing and swallowing; or through the use of therapeutic sources”.<sup>50</sup> While the descriptor provides room to consider whether someone needs prompting about appropriate portion sizes or to eat frequently enough, this will only be considered if the individual has a diagnosed eating disorder. Again, the potential for the PIP assessment to meaningfully consider psychological barriers to independent living and participation are understood in the most clinical and narrow sense.

These two descriptors are perfect examples of why the PIP assessment is not in fact a proxy for independence and participation. While being able to look after one’s nutritional needs is relevant to these goals, breaking the activity down to physical component parts within a strictly functional model does not yield useful information about what struggling with nutrition means for social inclusion.

#### Managing medication

Ability to adhere to antiretroviral medication safely on a daily basis is the only way to keep HIV under control in the body and avoid the development of serious HIV-related conditions. This is challenging for lots of people living with HIV, but particularly for those with additional support needs, such as those with mental health conditions or cognitive impairment.

The PIP descriptor managing therapy or monitoring a health condition considers capacity to appropriately take medication in a domestic setting, so should be relevant to these needs. However, common support needs that people living with HIV have in this area may be difficult to capture under the criteria. For example, someone who needs to be supervised when taking their therapy to avoid accidental or deliberate overdose will only attract one point under this descriptor.

#### Managing toilet needs

Persistent diarrhoea is a common symptom of HIV for those whose immune function has not recovered to normal levels. It is also a side-effect of certain HIV medications.<sup>51</sup> Capacity to keep diarrhoea under control is a source of stress, especially those who face mobility problems limiting their ability to reach a toilet in time.

The PIP assessment considers managing toilet needs or incontinence. However, ability to reach a toilet in time and other mobility concerns do not count towards the descriptor. Nor are barriers to moving around safely and quickly within the home considered elsewhere in the PIP criteria. However, someone who struggles to physically reach a toilet when at risk of bowel incontinence is likely to face barriers to independence and social inclusion. Once again the PIP descriptor is in practice a proxy for functional impairment, without consideration of the wider social determinants of participation.

#### Communication and social interactions

As with the descriptor on making and following a journey, under the mobility criteria, the engaging with other people face-to-face descriptor, under daily living, has the potential to identify the support needs of people living with HIV whose anxiety or depression forms a barrier to social participation. As with making and following a journey, however, the criteria show a clear bias towards instances where psychological distress can be attributed to a clinical diagnosis of e.g. generalised anxiety disorder, or agoraphobia.

#### CASE STUDY 6

##### **An HIV case worker in London describes supporting a client with cognitive barriers to communication:**

*“My client had a face to face, but was unable to effectively communicate with the HP due to severe cognitive problems. I advocated for her and she was awarded PIP.”*

50 DWP. PIP Assessment Guide. October 2016. p101

51 NAM. HIV treatment directory: diarrhoea. <http://www.aidsmap.com/page/1733062/>

### 3 A PROXY FOR WHAT? THE PIP ASSESSMENT

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It is worth noting, though, that this descriptor could apply to people living with HIV-related cognitive impairment. This group may also accrue points under one of the two communication-related descriptors, reading and understanding signs, symbols and words. However, people with cognitive impairment are explicitly excluded from scoring points under the other communication-related descriptor, communicating verbally.

#### Recommendations – improving the PIP assessment design

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It is time to look again at Personal Independence Payment and whether the assessment design, criteria and current approach to scoring are suitable for a benefit designed to promote participation and independence.

The Personal Independence Payment mobility criteria should be revised to:

- Remove the 20 metre threshold for the moving around descriptor, and replace with a 50 metre threshold.
- Create parity between psychological distress and sensory impairment, to the extent that these prevent someone from making a familiar journey without support.

In line with the functional approach taken by the Personal Independence Payment assessment, the impact of mental health-related barriers to participation daily living activities should not require a specific clinical diagnosis to be considered, where functional impact has been demonstrated.

The points thresholds for managing medication should reflect the seriousness of the health and disability impacts of failing to effectively self-manage treatments.

The impact on independence and participation of managing toilet needs when someone struggles to reach a toilet in time should be reflected in the relevant descriptor.

# 4

# HOW IS THE PIP PROCESS WORKING FOR PEOPLE LIVING WITH HIV?

**The PIP assessment includes important safeguards for people who experience fluctuation in their health, a concern for many people living with HIV. However, the way these rules are applied through guidance may limit their usefulness.**

**The PIP assessment is a source of stress for many people living with HIV who need significant support from specialised advice services to navigate the process.**

**Current approaches to gathering and weighing alternative sources of evidence are undermining trust in the assessment.**

People living with HIV have diverse needs and similarly diverse experiences of applying for PIP. Within this diversity, however, common themes emerge in how the PIP process has been experienced so far by people living with HIV. This section will draw upon the evidence and case studies we received from case workers and welfare rights workers supporting people living with HIV, both within HIV-specialist and generic advice services.

### Fluctuating symptoms

People living with HIV commonly experience fluctuation in their symptoms. An NAT survey found that of those who experience the most commonly-reported HIV-related symptoms, a significant proportion have variation over time. For example, 31% of those with neuropathy experienced variation in their symptoms, as did 24% of those who reported gastrointestinal problems and 38% of those with insomnia.<sup>52</sup>

Accurate assessment of fluctuating conditions has been a major source of concern around the Work Capability Assessment (WCA) for Employment and Support Allowance, which, like the PIP assessment, uses a series of functional descriptors which attract a score. The Independent Review of the WCA was sufficiently concerned to set up a programme of work investigating possible changes to descriptors, assessment practice and training to improve the accuracy of the WCA around fluctuation.

The development of the PIP assessment benefitted from some emerging lessons from the WCA work on fluctuation. The PIP assessment regulations, for example, enshrine – and define – key concepts used

<sup>52</sup> NAT. 2011. Fluctuating symptoms of HIV. <http://www.nat.org.uk/sites/default/files/publications/August-2011-Fluctuating-symptoms-of-HIV.pdf>

## 4 HOW IS THE PIP PROCESS WORKING FOR PEOPLE LIVING WITH HIV?

to capture the impact of fluctuation: the reliability criteria for completing an activity (safely, to an acceptable standard, repeatedly, and within a reasonable time period).

### PIP assessment reliability criteria and definitions:

Safely – in a manner unlikely to cause harm to themselves or to another person, either during or after completion of the activity

To an acceptable standard – (not defined)

Repeatedly – able to repeat the activity as often as is reasonably required

In a reasonable time period – no more than twice as long as the maximum period that a non-disabled person would normally take to complete that activity

Unlike the WCA, which classes someone as able to complete an activity if they can do it ‘on the majority of days’, the PIP assessment requires the HP to consider ability over a 12 month time-period, in acknowledgement that some fluctuation occurs over a period of weeks or months. In order to be classed as able to complete an activity under PIP, the claimant must be able to do it on more than 50% of days over the course of the year. This means that if someone experiences five months of being able to do the activity on a daily basis, followed by seven where it is not possible, they will be found unable to complete the activity.

In addition, if a claimant is unable to complete an activity at a particular time of day when it is reasonable to expect it to happen (e.g. getting up and dressed in the morning), then they are classed as not able to complete it.

These are important safeguards, but it is hard to know the extent to which these rules are applied in practice.

NAT is also concerned about how the reliability criteria are translated to practical situations in the PIP guidance to assessors. For example, HPs are given the following worked case study for applying the safety criteria to the moving around descriptor:

“Safety – there is no evidence that this activity poses any risk to Mr X’s safety. He said he experiences some pain and breathlessness and, while this may be uncomfortable, *he knows when to stop and rest* and there is no indication this causes him any harm.” (emphasis added).<sup>53</sup>

This example suggests that as long as the claimant shows insight into their symptoms, it would be hard to establish a safety risk to doing activities which cause pain or breathlessness. Along with the 20m rule, this may go some way to explaining the disparity we saw in case studies between support workers’ assessment of their client’s mobility barriers, and their assessment outcomes.

### Advocacy and support needs

The roll out of PIP has created a huge demand for support from advice organisations across the board. Citizens Advice has reported that in the 12 months to March 2017, PIP was the number one topic their clients sought help with; and that during this time they assisted with 400,000 problems relating to PIP claims, an increase in 37% from the previous year.<sup>54</sup>

As outlined in Section 1, the number of people living with HIV who have been assessed for PIP has so far been limited, compared to the number who will need to be re-assessed from DLA by the end of the roll-out. However, HIV organisations have consistently highlighted the intensive advocacy and support needs which their clients have needed to initiate, undergo and complete the assessment journey. Additional support is then needed for any reconsideration or appeal process.

In the case studies provided by HIV support services, the demand for advocacy and advice on PIP arises both from the pre-existing support needs that people who claim DLA and PIP will have; and

<sup>53</sup> DWP. PIP Assessment Guide. Point 3.3.42. p 94

<sup>54</sup> Citizens Advice responds to the second independent review of PIP. 30 March 2017. <https://www.citizensadvice.org.uk/about-us/how-citizens-advice-works/media/press-releases/citizens-advice-responds-to-the-second-independent-review-of-pip/>



## 4 HOW IS THE PIP PROCESS WORKING FOR PEOPLE LIVING WITH HIV?

from the specific requirements of the PIP application and assessment process. The former cannot be avoided, but should be anticipated by the DWP in designing an assessment process for people with severe health needs and disabilities. The latter is entirely within the control of the DWP.

### CASE STUDY 7

#### **An HIV-specific support service in the South of England describe how they supported a client:**

*“All steps in the application process were made by the support worker as this gentleman had a serious HIV-related brain injury and partner did not read/write. The evidence-gathering process consumed most time, especially waiting for confirmation letters from medical professionals. Our support worker provided help at each stage.*

*The face-to-face interview took an hour and half to complete; the support worker and the client’s partner were both present and provided additional evidence to support. The support worker drove the client to the face-to-face interview. A home visit was not requested as client has excellent mobility. The support worker advised our client on the process and what to expect. Our client found the interview bewildering but fine as felt supported by his partner and the support worker. He was given a chance to speak. In this instance there was no need to carry out a physical examination.*

*The client was awarded PIP daily living – enhanced rate. This was expected, given the nature of his brain injury. The impact has been predominantly positive: finances, health and well-being have improved as reduced worry about bills and ability to remain as independent as possible. It has also had a huge impact on his relationship with his partner as his partner was responsible for all bills for six months and had accumulated debts which have now been paid.”*

### CASE STUDY 8

#### **A London-based HIV organisation describe how it supported a client living with HIV, receiving DLA at the time of assessment, with complex needs relating to diabetes, schizophrenia, mobility problems relating to HIV neuropathy, depression and insomnia:**

*“The application was very difficult – she was unable to understand paperwork and each of the questions. Our keyworker went through the full form with her and he also contacted her doctors for medical evidence as she found the process overwhelming and quite distressing, as she had to explain that she was so ill (mentally) that she had chosen to give her son for adoption.*

*The keyworker attended with her. The interview lasted 45 mins. The client was very emotional and distressed throughout but she was not offered time to compose herself. She was too distressed to say what she wanted. The keyworker spoke on her behalf but he felt that his input was unheeded.*

*She was not awarded PIP. From next week, her payments will be reduced by £215 per week and she will not be able to survive on £115 per week. She is frightened, depressed and anxious. Her insomnia has become more profound and we are concerned that the stress might exacerbate the management of her schizophrenia.”*

In relation to Case Study 8, it is worth noting that the PIP assessment guide says that:

*“companions may play an active role in helping claimants answering questions where the claimant or HP wishes them to do so... However, the involvement of companions should be at the discretion of the HP. It is essential that the HP’s advice is based on the claimant’s actual circumstances and not the companion’s view of these.”<sup>55</sup>*

55 DWP. PIP Assessment Guide. October 2016. point 2.7.2. p 43.

## 4 HOW IS THE PIP PROCESS WORKING FOR PEOPLE LIVING WITH HIV?

This advice is appropriate as a statement of principle for impartial assessment, however, it doesn't address the subtleties of the sort of situation described by the case study, where an advocate attempts to speak for a client who is too distressed by the interview to provide the evidence she wishes to. A companion speaking on behalf of a claimant is not necessarily expressing their own opinion.

Demand for help with PIP applications is rising at a time of rapid disinvestment in the HIV support services which provide this advocacy, especially in England and Wales.<sup>56</sup> Given the ambitious time-scales to complete the PIP roll-out, and the number of people living with HIV whose DLA claims have not been re-assessed, this demand seems set to grow exponentially in a short time.

### Experience of the face-to-face consultation

The face-to-face consultation component of the PIP assessment emerges as a major cause of stress in the case studies from HIV support organisations, including in those cases where PIP was awarded as a result of the consultation.

#### CASE STUDY 9

##### HIV welfare rights advisor in London:

*"The interview was a stressful experience, even though the assessor was pleasant. Yes, client had a chance to explain his conditions and the way they affect him. Physical examination was performed after client's permission... It was a stressful process, but client is in much better financial position than prior the claim."*

The ease of arranging a home visit differed across areas. One HIV organisation based in London noted that it was extremely difficult to arrange one, even where there was strong medical evidence for why it was needed – for example, in the case of a claimant who had TB with mobility and breathing difficulties. A home visit was agreed in the end, but it took a long time to arrange. There are a number of case studies

56 In England there has been a 28% reduction in investment in these services in a single year. NAT. 2017. HIV Support Services: the state of the nations. [http://www.nat.org.uk/sites/default/files/publications/NAT\\_HIV\\_Support\\_Services\\_The\\_state\\_of\\_the%20nations%20\\_2017\\_FULLL.pdf](http://www.nat.org.uk/sites/default/files/publications/NAT_HIV_Support_Services_The_state_of_the%20nations%20_2017_FULLL.pdf)

where home visits were clearly an appropriate option for people living with HIV who had health-related barriers to travel, and these were provided. However, home visits were not necessarily less stressful experiences. One London support service reported that they needed to send a case worker to attend a client's home visit for emotional support and because "she was scared to have two men coming to her place."

#### CASE STUDY 10

##### HIV case worker in West Midlands:

*"My client had a home visit (as requested) although the assessment provider wasn't able to contact me to make the appointment so I could be present for the interview. My client got confused with all the dates on which I said I could attend. After she changed the date a couple of times the assessment provider wasn't able to change it a further time. Her partner attended instead of me. My client felt the interview was invasive and felt intimidated."*

For people living with HIV, who have often experienced stigmatising and discriminatory behaviour relating to their condition, the stress of the face-to-face interviews takes on a unique dimension. The 2015 UK people living with HIV stigma survey found that one in eight respondents had avoided seeking healthcare in the past year, because of stigma-related concerns. Around a third worried about being treated differently by their GP because they were living with HIV.<sup>57</sup> When the experience and fear of HIV stigma colours interactions with core health and care services, it is clear why interacting with an unknown HP, employed by a private company to carry out a benefits assessment, can cause stress and a sense of vulnerability for people living with HIV who have complex support needs.

The case studies provided to NAT included positive comments about the behaviour of HPs, for example, that they were 'pleasant' and 'very understanding'. However, there were also comments about HPs who were less helpful in their approach. For example, one

57 Survey of 1576 people living with HIV, conducted with the support of Public Health England. The People living with HIV stigma survey. 2015. HIV in the UK: Changes and challenges; Actions and answers. National report. <http://www.stigmaindexuk.org/reports/2016/NationalReport.pdf>

## 4 HOW IS THE PIP PROCESS WORKING FOR PEOPLE LIVING WITH HIV?

support worker attended a face-to-face interview where the HP asked someone with mental health problems, “do you think that’s because you’re a gay man?” Another support worker told NAT that she thinks HPs have “assumptions about what people living with HIV look like... and a model of what it means to not be doing well with HIV.”

### Trust in the process

The second independent review of the PIP assessment found that “public trust in the fairness and consistency of PIP decisions is not currently being achieved, with high levels of disputed award decisions, many of them overturned at appeal.”<sup>58</sup>

This lack of trust is reflected in the evidence provided by support services who assisted people living with HIV through the process. A common theme in comments from welfare rights advisors was that they felt the HP was trying to catch out their client, or find reason to disbelieve the evidence they had provided about their health. As one advice worker based in the West Midlands put it, “from the moment you walk in, before the assessor even sees you, you’re being assessed... they know exactly how long their corridor is and they’ll take that as a basis for everyday life, even though that’s not what the rules of PIP say [to do].”

The PIP guide for HPs provides clear guidance that:

“Throughout the consultation, HPs should be evaluating what they are being told and checking whether the evidence is consistent. Inconsistencies could result in claimants either over or under emphasising the impact of their conditions and efforts should be made to avoid both.”<sup>59</sup>

Although the guidance makes clear that it is equally the role of HPs to check whether claimants may be under-playing the impact of their condition/s, the dominant reaction of claimants and their advisors is that inconsistencies are sought because of mistrust in claimants – which in turn is breeding mistrust of the process.

### CASE STUDY 11

#### HIV case worker in West Midlands:

*“I had one claimant with severe anxiety problems. The report came back: ‘the person didn’t seem to be anxious at all’. This is a common approach – visible judgements. The report will say someone with depression ‘has a good insight into their health condition’, like that is bad thing for PIP eligibility.”*

In addition to specific concerns about a disproportionate focus on inconsistencies, HIV-specialist advisors more broadly questioned the extent to which HPs rely on their own observations of the claimant, over other sources of evidence the claimant has provided. Again, this is a practice which is encouraged by the official guidance to HPs, which states that “informal observations are of paramount importance to the consultation.”<sup>60</sup>

### CASE STUDY 12

#### Case worker in a non-HIV specific service in Brighton:

*“I had a client who dropped out of university because of crippling anxiety, applied for PIP and was awarded the standard rate daily living and mobility. She is currently appealing the PIP decision because we think she should get the enhanced rate. The PIP medical assessor noted that because she had been at university, she had no cognition problems and therefore presumably would not suffer from mental health issues which would affect her daily life!”*

58 Paul Gray. 2017. The Second Independent Review of the Personal Independence Assessment. p.3  
[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/604097/PIP-assessment-second-independent-review.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/604097/PIP-assessment-second-independent-review.pdf)

59 DWP. PIP Assessment Guide. October 2016, p35.

60 DWP. PIP Assessment Guide. October 2016, p39.

### Recommendations – improving the PIP process

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The Personal Independence Payment Assessment Guide for assessment providers should also be reviewed, with attention to:

- Applying the reliability criteria in a way which increases the accuracy of assessments for people with fluctuating conditions.
- Collecting complete evidence first-time around, with appropriate weight to responses made by the claimant and their companion where applicable, to reduce the need for reconsideration and appeal.
- Using alternative sources of additional evidence to facilitate a greater proportion of paper-based assessments, for people with complex needs.
- How guidance on informal observations contributes to lack of trust in the fairness and accuracy of the assessment.
- Identifying positive actions to help reduce the anxiety and stress experienced by claimants, especially those with stigmatised conditions.

Advice and support services which support people living with HIV through the Personal Independence Payment assessment need to be appropriately funded. There should also be greater recognition of the resources which health, care and voluntary sector support professionals contribute to the success of assessments.

Services supporting people living with HIV who claim Disability Living Allowance should prepare themselves and their clients for Personal Independence Payment re-assessment, including financial planning support for those who may lose some or all of their support, without causing undue fear.

Clinicians providing evidence to support Personal Independence Payment assessments should familiarise themselves with the functional nature of the assessment and content of the descriptors, to ensure it is as relevant as possible to their patients' claims.

# CONCLUSION

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**Only a minority of DLA recipients living with HIV who will ultimately need to be re-assessed for PIP, have been through the assessment. Even at this early stage, however, it is clear that the PIP assessment is not fairly or accurately capturing some of the key barriers to participation and independence experienced by people living with HIV.**

**People living with HIV and the services which support them are not confident in the accuracy or fairness of assessments.**

**While there have been independent reviews of the implementation of PIP, the key problems identified in this research arise from the fundamental assessment design and criteria, and DWP policy about how to apply these. It is time to look again at PIP.**

# SHAPING ATTITUDES CHALLENGING INJUSTICE CHANGING LIVES

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