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**THE IMPACT OF THE WELFARE  
REFORM ON PEOPLE LIVING  
WITH HIV IN ENGLAND**

*Summary Report – March 2014*

HUNGER  
ESA  
POVERTY  
WELFARE  
HIV  
STRESS



COUNTERPOINT POLICY ALLIANCE



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# THE IMPACT OF THE WELFARE REFORM ON PEOPLE LIVING WITH HIV IN ENGLAND

## Foreward

There is no arguing that development of successful antiretroviral treatment (ART) is one of the greatest advances in medicine in the last 50 years. However effective treatment does not completely negate the impact of HIV on well-being. People living with HIV (PLWH) continue to disproportionately experience poor physical and mental health, along with stigma, poverty and social isolation.

Support from the welfare system for PLWH is critical and changes to welfare eligibility or the level of support provided may have dramatic effects. These effects can be seen in clinic; increased anxiety and depression, people reporting they cannot afford food, difficulties with adherence due to poor housing, reduced access to care. While most HIV service providers can confirm these reports up until now these have been mostly anecdotal. This report is welcomed. It begins to describe just how far reaching the impact of these welfare changes have been.

However this is not only a report of the problems but also a document for the future. Recommendations include those for policy change, for commissioning and also for service provision. In my own clinical area the recommendation for advice services to operate within or alongside health services is a welcome one and rightly brings us full circle. It is recognition that an undetectable viral load, while a very good thing, is not necessarily a panacea.



**DAVID ASBOE**

*Chair, British HIV Association*

## Background

This research report was initiated by the Counterpoint Policy Alliance (Counterpoint), a collaboration between Naz Project London, Positive East and Positively UK. This study builds on research conducted in 2010 by Counterpoint on possible responses in the HIV sector to the challenges raised by the financial downturn. The 'Securing our Future' report revealed a steady but persistent reduction in the services available for people living with HIV (PLWH) which posed challenges to the HIV sector in its HIV response (Counterpoint, 2011).

The challenges to an effective response to HIV in the UK have since continued with the Government introducing fundamental changes to the welfare system, and an overhaul of the National Health System (NHS). This second Counterpoint Policy Alliance study captures the initial impact that these reforms have had on PLWH, and reflects on some of the issues identified in the previous report.

On the basis of the evidence uncovered in our survey of over 280 PLWH in England, this report puts forth nine recommendations which aim to shape thoughts on how best the government, commissioners and the organisations working with PLWH and indeed other long-term conditions could respond to some of the challenges that these individuals face in the midst of welfare reform.

## Context

Health Protection England estimated that in 2012 there were 100,000 individuals who lived with HIV in the UK (HPA, 2012). Health inequalities and poor health outcomes are inextricably linked to poverty and social justice (Fair Society, Healthy Lives, Marmot, 2008). One in six people who are diagnosed with HIV in the UK experience severe poverty (NAT, THT, 2010). This poses a great challenge to PLWH who rely on benefits as a result of their condition, and to service providers as they must respond to the increasing demand for their services in the midst of budgetary cuts. These cuts undermine a fundamental aspect of the NHS outcome framework, the one which aims to enhance the quality of life of people with long-term conditions and to promote access to employment.

In addition, the welfare reform and service reductions put at risk the following three key objectives of the recently published Department of Health's Framework for Sexual Health Improvement in England (2013):

- People remain healthy as they age
- Rapid access to high quality services
- Reduce onward transmission of HIV

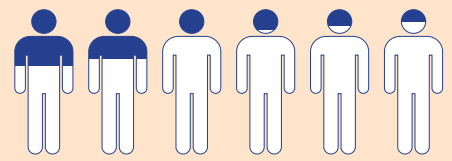
Counterpoint Policy Alliance decided to investigate the extent to which PLWH in England were directly affected by welfare reform, and how these changes impacted on their financial situation, their health and well-being, their quality of life and access to HIV support and care.

### WHO WE REACHED



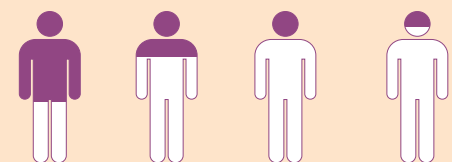
**287 ADULTS**

*who live with HIV were surveyed.  
33 of the records were incomplete.*



**White British African Latin America Western European South Asian Other**

*35 % identified themselves as White British, 30 % as Africans, 11% as Latin American, 10% as Western European, 9% as South Asian and 5% as Other.*

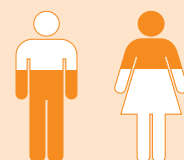


**Gay/MSM Heterosexuals Bisexuals Did not disclose**

*54% of the respondents identified themselves as Gay/MSM; 38% as Heterosexuals, 5% as Bisexuals and 3% as 'did not disclose'*

**44 YEARS**

*Respondents had an average age of 44 years.*



**70% 30%**

*The majority of the respondents were male (70%). The other 30% were female.*

**22% EMPLOYED**

*A third of the respondents said that they are unable to work because of their long-term illness or disability or because they are medically retired. Only 22% of the respondents were in full time employment.*

# CHANGES IN THE BENEFIT SYSTEM ON PLWH

## Key Findings

- Two thirds (66%) of PLWH were affected by the benefit changes, and from these nine out of 10 reported a negative impact on their health or on their access to HIV care. Those reporting no changes to their circumstances are mostly those not receiving benefits.
- The number of benefit changes individuals go through (or will go through) makes a significant difference to their health and well-being and access to HIV services.
- The medical assessments of PIP and ESA are not addressing the barriers, including psychological factors and lack of relevant skills, that impact upon many people with disabilities and long-term conditions, including PLWH, when seeking work.
- Respondents in this survey reported significant service reductions in HIV and non-HIV specific services offered by charities.
- Women from BAME communities, Latin Americans and White MSM over 50 were hit particularly hard by the changes in the welfare reform.
- There is a serious mental health issue caused by the shame and stigma that respondents feel when applying for benefits.

## Changes in Employment and Support Allowance (ESA)

- 72% of the PLWH had a negative experience while being assessed for ESA and close to half of them had a very negative experience during the assessment process.
- The issues with the assessment process are reflected in the high number of those who appealed ESA decisions and were successful (36%).

## Replacement of the Disability Living Allowance (DLA) by the Personal Independence Payment (PIP)

- 20% of our respondents were directly affected by the replacement of the DLA by PIP and 25% said that they would be affected in the future.
- This is especially the case among white MSM over 50. While 25% of the white MSM respondents over 50 have already been affected by the introduction of PIP, another 50% will be affected by its future introduction.

### RESPONDENT'S COMMENTS

#### Respondents noted the difficulty and stress of applying for ESA:

*'The ESA re-assessment is particularly challenging as you only have 4 weeks to get the information back to ATOS. This can be difficult for people with mental health problems & also gathering evidence takes time to support the paper assessment.'*

*'Had to appeal against my medical assessment. When went to appeal it was given to me and not only that they decided I should have been in support group of ESA. This is so stressful and makes problems worse when having to appeal and money reduced until it is sorted.'*

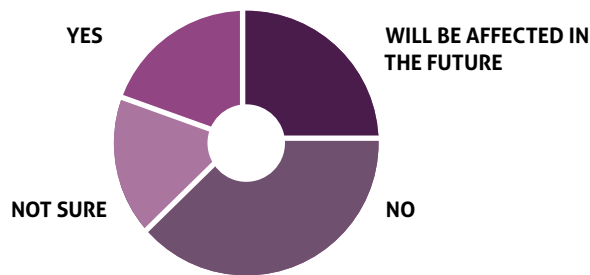
#### The anxiety and the stress that PLWH experience because of the changes in the DLA can be seen in some of their comments:

*'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.'*

*'PIP medical assessment very distressing. I don't want to discuss my HIV status with a stranger.'*

# CHANGES IN THE BENEFIT SYSTEM ON PLWH

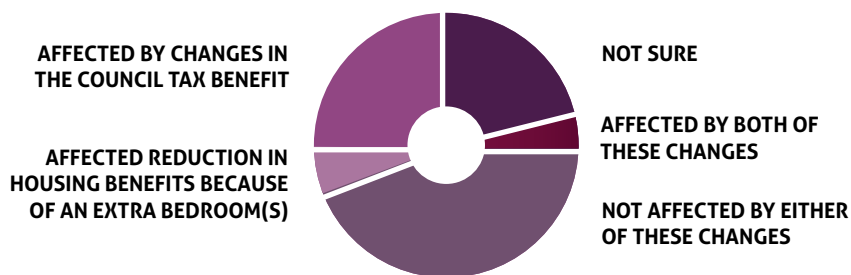
FIGURE 1: ARE YOU DIRECTLY AFFECTED BY THE REPLACEMENT OF THE DLA BY THE PIP?



## Changes in Housing Benefits

- 39% of respondents were either affected by the council tax reduction, the reduction in housing benefits because of an extra bedroom (commonly called 'bedroom tax') or by both changes simultaneously.

FIGURE 2: % OF PLWH DIRECTLY AFFECTED BY THE HOUSING BENEFITS CHANGES



- BAME women have been hit particularly strongly by the changes in housing benefits. 70% of BAME women respondents were either affected by the council tax reduction, the reduction in housing benefits because of an extra bedroom(s) or by both.
- Respondents who live in London were significantly more affected by the housing benefits than respondents living outside London, 53% as compared to 35%, respectively.

## The Introduction of the Benefit Cap

- 19% of respondents were affected by the 'benefit cap' and 17% will be affected by it in the future.
- While 12% of the male respondents were directly affected by the benefit cap, 32% of the female respondents were affected, and this is especially the case for women of BAME communities.

## Concern with the Implementation of the Benefit Changes

Respondents raised concerns with the way in which the changes in the benefits system have been managed. They noted a fragmentation of the benefit system and a lack of communication between entities responsible for administering the system.

### RESPONDENT'S COMMENTS

The fear of becoming homeless as a consequence of the housing benefit changes was illustrated in a comment left by a respondent:

*'I have been made homeless in the past and the thought of going through it for a third time whilst ill nearly destroyed me and for the first time ever I began to want to end my own life.'*

Changes to the housing benefits are not modifications of existing benefits but new financial pressures put on PLWH:

*'I wasn't required to pay Council Tax before, and now I must pay about £60 and I can't afford it as other things like food are more important.'*

Comments concerning the implementation of the benefit changes:

*'It's hard to negotiate a fragmenting system even if one is engaged and willing to try.'*

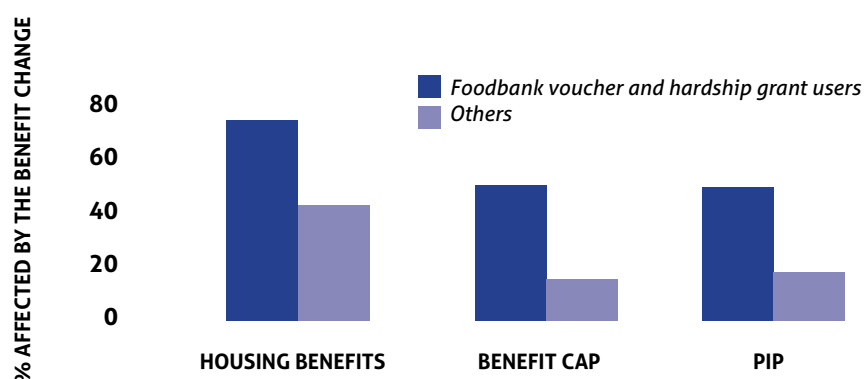
*'The whole system is a nightmare with dozens of departments with separate locations & contact details. I feel even with a good education and excellent levels of \*know how\* it's never easy and always frustrating. Some people probably fail through lack of understanding or give up.'*

# IMPACT OF THE BENEFIT CHANGES ON PLWH

## Financial Impact

- 58% of the individuals surveyed, and 73% of the African PLWH surveyed, have seen their financial situation worsen over the past 12 months.
- One out of five PLWH surveyed had either applied for a hardship grant, redeemed a foodbank voucher or had done both.
- The percentage of respondents affected by benefit changes is significantly higher among those who have made use either of a foodbank voucher, a hardship grant or both. The problem may even be larger than what has been portrayed here as not all were aware of these forms of assistance and many admitted that they were too embarrassed to use them.

FIGURE 3: BENEFIT CHANGES ACCORDING TO FOODBANK VOUCHER AND HARDSHIP GRANT USE



## Welfare Reform and the Impact on the Mental and Physical Health of PLWH

- 62 % of respondents experienced a negative impact on their mental health and well-being, and over half of respondents (53%) reported a negative impact on their physical health as a result of the benefits changes. Less than 3% stated that the changes in the welfare reform had had a positive impact on their mental or physical health and wellbeing.
- BAME women and White MSM over 50 reported significant negative impacts on mental and physical health. 78% of BAME women reported a negative change in their mental health and well-being and 69% of them a negative change in their physical health. 71% of white MSM over 50 reported a negative change in their mental health and well-being.

### RESPONDENT'S COMMENTS

The comments from respondents highlight the extent to which PLWH are facing financial problems:

*'Find things struggle much more than before. Can't afford to eat, bills are overdue with threat of disconnection.'*

*'I am struggling financially but as I have never been out of work prior to my condition, I do not know all the benefits I can received, I have never heard of the Hardship Grant or foodbank.'*

*'I'm too embarrassed to use Food banks and if I lose my ESA benefit I will lose my home because I will not be able to afford my Bills.'*

The comments left by the respondents strongly suggest that they experience mental health issues caused by the shame and stigma they feel when applying for benefits:

*'I feel terrible shame at having HIV and even more shame at not being able to cope very well [...] I have become very aware of how people's attitudes have changed towards people on benefit I have felt peoples prejudice and at times felt discriminated against.'*

*'Because of media/Tory comments, I am made to feel like trash socially because I am on benefits.'*

*'I was on IC Benefit but I was sent to ATOS for assessment and lost I have since appealed and I am waiting to attend Tribunal for my case to be heard for ESA. I find the whole process is making me feel suicidal and it is effecting me with my HIV treatment.'*



# IMPACT OF THE BENEFIT CHANGES ON PLWH

## Impact on the Access to HIV Services of PLWH

- Over 45% of respondents stated that they had seen a negative impact on their access to HIV care, treatment and support over the last 12 months, with over a fifth of respondents noting a significant negative impact. Only 2% of respondents noted a positive change to such access.
- While 37% of MSM/Gay men respondents reported a negative impact on access to HIV care, treatment and support, the corresponding figure for women was 51%.
- 46% of BAME respondents stated that there had been a negative change in their access to HIV care, treatment and support; this was highest for Latin Americans at 67%.

## Impact on the Services Delivered by HIV Charities

- A third of the respondents saw a negative change in HIV services delivered by charities, and 45% of respondents saw negative changes in non-HIV specific services delivered by charities in the last 12 months. Only 6.6% and 2.1 % saw positive changes, respectively.

FIGURE 4: NEGATIVE CHANGES IN HIV SERVICES DELIVERED BY CHARITIES IN THE PAST 12 MONTHS

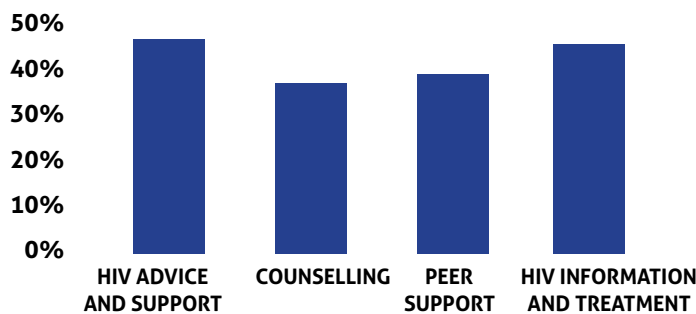
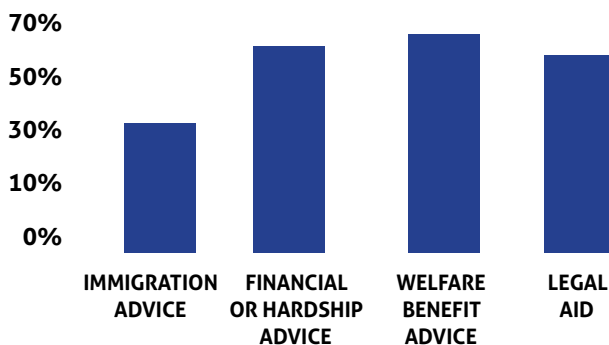


FIGURE 5: NEGATIVE CHANGES IN NON-SPECIFIC HIV SERVICES DELIVERED BY CHARITIES IN THE PAST 12 MONTHS



### RESPONDENT'S COMMENTS

#### Respondents gave indications of the extent of service reductions:

*'Funding was withdrawn from a positive men's group I attended. The group stopped. I lost contact with other positive people.'*

*'Hospital and social worker assistance reduced - longer time intervals between sessions.'*

*'Mental Health services seem to be particularly squeezed in West London. Referrals take a long time to turn around. I now have to co-ordinate the links between GP/HIV Clinic & Mental health to access a "joined up" system.'*

#### Respondents mentioned that they were not aware of some of the benefits they could apply for:

*'I am anxious of what is next. I didn't have idea that I can apply for some of the benefits that are in this survey. I just learned now - but how do I do it?'*

#### Others emphasised the difficulty of keeping up with the many changes in benefits. Targeted assistance by charities is thus vital:

*'There are too many changes in such a short period of time. It is very chaotic and confusing'.*

*'Complicated, and difficult to understand, for both my officer and myself'.*

*'I struggled to find out what support was out there. The HIV charity in Manchester is over-subscribed and I have to work through all the barriers mostly on my own [...] HIV charities should be able to provide more personal support.'*

# IMPACT OF THE BENEFIT CHANGES ON PLWH

## Summarising the Impact of the Benefit Changes on Respondents

The data shows a stark contrast in the impact on physical/mental health and on access to HIV treatment, care and support between respondents affected by benefit changes and those who were not.<sup>1</sup>

PIP REASSESSMENT	PHYSICAL HEALTH IMPACT	MENTAL HEALTH IMPACT	ACCESS IMPACT
No PIP reassessment	-0.39	-0.45	-0.37
PIP reassessment now or in the future	-1.11	-1.35	-0.87

BENEFIT CAP	PHYSICAL HEALTH IMPACT	MENTAL HEALTH IMPACT	ACCESS IMPACT
Not affected by the benefit cap	-0.49	-0.61	-0.38
Affected or will be affected by the benefit cap	-1.24	-1.46	-1.05

HOUSING BENEFIT	PHYSICAL HEALTH IMPACT	MENTAL HEALTH IMPACT	ACCESS IMPACT
Not affected by a housing benefit change	-0.55	-0.61	-0.44
Affected by the reduction in housing benefits because of an extra bedroom(s) or the council tax reduction	-1.14	-1.38	-1.00
Affected by both the reduction in housing benefits because of an extra bedroom(s) and the council tax reduction	-1.31	-1.57	-1.00

The data also strongly suggests that the number of benefit changes individuals go through (or will go through) makes a significant difference to their health and well-being and access to HIV services. The 'impact index' score is the sum of the impact on physical health, on mental health and well-being and on access to HIV care, treatment and support as a result of benefit changes.

NUMBER OF BENEFIT CHANGES	0	1	2	3	4
Average 'Impact Index' score (range: -6 to 6)	-0.9	-2.3	-3.3	-4	-4.6
Average Financial Impact score (range: -1 to 1)	-0.28	-0.38	-0.72	-0.76	-1

<sup>1</sup> The average scores in the three tables (range: -2 to 2) were obtained by translating answers into numbers as follows: significant negative impact (-2); negative impact (-1); no change (0); positive impact (1); and significant positive impact (2).



# RECOMMENDATIONS

## Recommendations for welfare policy

- There is a clear conflict in the impact of welfare reforms upon the Government's aim to promote well-being and quality of life as outlined in the health and social care outcomes frameworks. A whole system review to link all these areas together is required to ensure the cumulative burden from multiple benefits changes is not pushing PLWH into critical poverty. This cumulative burden exacerbates physical and mental health issues, compromises quality of life and undermines national health outcomes.
- The medical assessments for ESA and PIP need to be based on the social model of disability in order to take into account the barriers, including psychological factors and lack of relevant skills, that impact upon many people with disabilities and long-term conditions, such as PLWH, when seeking work. Assessments also need to be tailored to better reflect the complex and fluctuating nature of HIV and its treatment. This could be achieved through the involvement of advocacy agencies and people living with long-term conditions including HIV in the re-design of assessments and guidance of HIV health professionals in the assessments.
- DWP and ATOS staff should receive specialist training in understanding long-term conditions, including HIV, the impact of treatments and ramifications for people's health and well-being.
- Provision of stable, accessible and good quality housing and access to a nutritional diet is crucial in supporting PLWH to access consistent treatment, to maintain their health and to improve their quality of life. There is a need for the better integration of housing interventions and welfare support into comprehensive HIV care and healthcare overall.

## Recommendations for commissioning and service provision

- The stigma associated with HIV leaves many people socially isolated and reliant on the voluntary sector and peer support services. In our 2011 survey we noted that PLWH "saw the decline in access to services as a risk to their well-being and to their management of their HIV diagnosis" (Counterpoint 2011: 5). Respondents in this survey have reported serious reductions in services offered. These service reductions are now even more problematic, given the vulnerability of PLWH amidst welfare reforms. It is now more important than ever that PLWH access a good quality social security benefit and housing information, advice and advocacy services provided by organisations with specialist understanding about HIV.

## RECOMMENDATIONS

- Women from black and minority ethnic groups, Latin Americans and gay men/MSM over 50 are especially vulnerable to the impact of welfare reform. HIV and social support programmes need to take into account the needs of these groups in order to safeguard them from the most damaging effects when transitioning to the new system. This will only be possible with sustained funding in HIV services.
- The need for advice services to operate within, or alongside, health and well-being services should be taken into account in all future commissioning. These services are vital if PLWH are to be able to manage their health and well-being within the context of welfare reform.
- People living with HIV face many barriers to accessing services, not least because of the fear of discrimination. HIV charities have specific knowledge of these issues and are best placed to support people in accessing education, training and employment services and opportunities.

### Recommendation for the media

- The stigma that arises from people claiming benefits needs to be tackled. Welfare is there to provide a safety net, and to help people who are ill, homeless or who lost their jobs live dignified lives. As such, people who claim benefits should be treated with respect. The media, by only reporting on benefit frauds and by portraying benefit claimants as 'scroungers', increases the stigma felt by many already marginalised and vulnerable groups and may deter people accessing the necessary support resulting in poorer physical and mental health.

# ACKNOWLEDGMENTS AND CONTACTS

## Acknowledgments

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Thanks to Sigma Research for their guidance on questions and on the structure of the survey.

We would like to sincerely thank all of the individuals who took part in this survey and the charities who promoted the survey and who disseminated it through their networks.

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## List of contributors

### Project Directors:

Allan Anderson, CEO, Positively UK  
Mark Santos, CEO, Positive East,  
Marion Wadibia, CEO, Naz Project London

### Lead Researcher:

Ivana Paccoud, Policy and Research Officer, Naz Project London

### Design:

Clarissa San Pedro

The full report can be downloaded from the Counterpoint Policy Alliance website:

<http://www.counterpointpolicyalliance.org.uk/>

If you have any questions about this project, please email [ivana@naz.org.uk](mailto:ivana@naz.org.uk)

## Contacts

### Naz Project London

30 Blacks Road, Hammersmith, London W6 9DT

Phone: 020 8741 1879

[npl@naz.org.uk](mailto:npl@naz.org.uk)

Registered Charity No. 1014056

### Positive East

159 Mile End Rd, Stepney Green, London E1 4AQ

Phone: 020 7791 2855

Email: [talktome@positiveeast.org.uk](mailto:talktome@positiveeast.org.uk)

Registered Charity No. 1001582

### Positively UK

345 City Road, London, EC1V 1LR

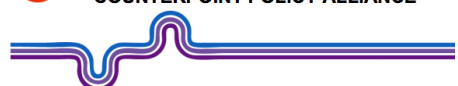
Phone: 020 7713 0444

Email: [info@positivelyuk.org](mailto:info@positivelyuk.org)

Registered Charity No. 1007685



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