



House of Commons Public Bill Committee – Welfare Reform Bill Submission from NAT (National AIDS Trust)

Summary

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.

NAT is a member of the Disability Benefits Consortium (DBC), and we support the DBC submission on the Welfare Reform Bill.

We wish to provide evidence on how two aspects of the Welfare Reform Bill in particular will have a serious impact on the health and well-being of people living with HIV who claim benefits:

Time-limiting the payment of contributory Employment and Support Allowance (work related activity group) to twelve months.

To set a time-limit on receipt of the main out of work benefit for those whose capacity for work is limited by their HIV will leave many at risk of poverty. Many people living with HIV who are found eligible will face significant barriers to work that cannot be overcome within 12 months. Additionally, many will face HIV-related stigma which will further limit their capacity to find work within that time-frame.

Introducing Personal Independence Payment to replace the current Disability Living Allowance

DLA is an important benefit for people living with HIV to help them stay well and participate fully in society, including work. NAT is concerned that the new assessment for Personal Independence Payment will have the same problems as the current assessment for Employment and Support Allowance, which does not accurately assess the main barriers experienced by people living with HIV. In addition, the stated intention to focus DLA on those in greatest need is likely to affect many people living with HIV for whom DLA currently has a vital preventive and health-promoting role.

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HIV and benefits

1. HIV is a disability.¹ Individual experiences of living with HIV vary greatly, and the impact of HIV upon daily living and ability to work is equally varied. Some people may be in very poor health as a direct result of HIV-related illness; others may experience less visible, fluctuating or episodic symptoms such as fatigue and mental health problems (and of course many are able to lead active, healthy lives).
2. Between 2006 and 2009, one in six people being treated for HIV in the UK were living in such poverty that they applied for charity assistance of emergency cash payments. Among those who received this assistance, the second most cited reason for their financial hardship was that they were reliant on benefits.²

Time-limiting the payment of contributory Employment and Support Allowance (work related activity group) to twelve months

3. The loss of the key out of work benefit for those with a disability or illness at an arbitrary point will exacerbate the existing high levels of poverty among people living with HIV, as described above. Living in poverty seriously compromises the ability of people living with HIV to meet their health-related needs. This includes the very basics such as travelling to medical appointments, heating their home to prevent respiratory infection, and regularly eating nutritious food to ensure the success of their treatment regime.
4. Physical and mental health problems related to HIV do not come with a time limit. These may include opportunistic infections and HIV-related illness; side-effects from treatment including diarrhoea, nausea, insomnia and fatigue; and depression and anxiety, which disproportionately affect people living with HIV.³
5. Substantial barriers to work must be demonstrated before the work-related activity group (WRAG) rate of ESA can be paid. For example, someone who experienced a combination of severe HIV-related treatment side effects – lipoatrophy (fat loss) affecting the pads of the feet, and frequent diarrhoea - would not be found eligible, even if it was shown that they:

Risk losing control of bowels or bladder so that the claimant cannot control the full evacuation of the bowel or the full voiding of the bladder if not able to reach a toilet quickly (6 points)

Cannot walk more than 200 metres on level ground without stopping or severe discomfort (6 points)⁴

If someone living with HIV with these two conditions is ineligible for ESA (WRAG), it is clear that anyone who *is* found eligible already has very significant barriers to work, and should not be punished because they have not been able to access suitable work within 12 months.

¹ And is defined as such from the point of diagnosis, under the Equality Act 2010,

² NAT and THT. "Poverty and HIV: 2006 to 2009".

<http://www.nat.org.uk/Media%20library/Files/Policy/2011/HIV&Poverty.pdf>

³ NAT. 2010. Psychological support for people living with HIV.

<http://www.nat.org.uk/Media%20library/Files/Policy/2010/Psychological%20support%20July%202010%20updated.pdf>

⁴ A total of 15 points is needed to enter the WRAG

6. In addition, HIV remains a stigmatised condition in the UK, so people living with HIV still face social, as well as health-related, barriers to work. Research shows that unemployment among people living with HIV may be as high as 50%.⁵ One in five people living with HIV who are in work have experienced discrimination in either their previous or current job.⁶
7. Once the 12 months of contributory ESA has expired, the claimant may apply for income-based (means-tested ESA), but many will not be eligible. For example, anyone who has a partner working more than 24 hours per week will not be found eligible. This leaves people living with HIV in an extremely vulnerable position. The financial stress associated with the loss of their primary income (£91 per week) is likely to negatively affect their health and ability to manage their treatment, which in turn will reduce their capacity for work in future.

Recommendations

8. The Committee should seek clarification on the following aspects of the provision to time-limit contributory-based ESA (WRAG) to 12 months
 - What will happen to claimants who reach the 12 month limit of contributory ESA (work-related activity group) but do not qualify for means-tested ESA?
 - What evidence did the Government use to decide upon the 12 month limit for ESA?
 - Has the Government considered the additional difficulties people with stigmatised conditions such as HIV, will have in trying to find work within 12 months?
9. Clause 51(1A) should be removed from the Welfare Reform Bill.
10. Alternatively, if the Government proceeds with time-limiting contributory ESA, the time limit should be extended to a minimum time period of 24 months.

Introducing Personal Independence Payment to replace the current Disability Living Allowance

11. More than 1 in 10 people currently accessing HIV care in the UK is in receipt of Disability Living Allowance (DLA).⁷ A recent survey found that for people living with HIV, the top uses for DLA were:
 - **paying bills:** the need to keep a home well-heated because of susceptibility to respiratory problems can drive up utilities bills
 - **buying food and other essentials:** particular nutritional needs associated with HIV treatment can make food shopping expensive; and essential

⁵ Over 50% unemployment in a study of people living with HIV in East London. Ibrahim, F et al (2008). "Social and economic hardship among people living with HIV in London". *HIV Medicine*.; 38% of 250 respondents in a recent NAT online survey of people living with HIV (report forthcoming).

⁶ NAT. 2009. *Working with HIV*.

<http://www.nat.org.uk/Media%20library/Files/Policy/Our%20thinking/Employment%20summary%20report%20-%20FINAL%20August%202009.pdf>

⁷ 7500 out of 61100 individuals (12%). 2008 DLA statistics obtained with an FOI request, and HPA figures on HIV care access for the same year.

personal care needs such as continence pads (a common side-effect of treatment is diarrhoea) also add to grocery bills

- **transport and the motability scheme:** living with pain, fatigue and specific HIV-related conditions such as neuropathy (nerve pain) create a need for help with transport such as taxis or motability vehicles.
 - **paying for help or support:** conditions such as neuropathy may lead to the need for assistance with food preparation and household cleaning; social care and psychological support may also be crucial in helping people living with HIV effectively manage their treatment.⁸
12. NAT welcomes the intention to maintain PIP as an extra-costs benefit, which is tax free and non-means tested.
 13. In addition, NAT agrees with the decision to update the proxies used to determine eligibility for PIP: the move from 'care' to 'daily living' in recognition that extra costs associated with disability are not only related to care needs; and the broader definition of 'mobility' to include all aspects of getting around, not just whether or not someone can walk without difficulty.

The assessment for PIP

14. NAT is concerned that the intention to introduce face-to-face meetings with healthcare professionals for almost all PIP claims will create many of the same difficulties already experienced with the Work Capability Assessment (WCA) for Employment and Support Allowance (ESA), which is a very similar model.
15. NAT's research found that the barriers to work experienced by people living with HIV, such as severe immune deficiency, side-effects of treatment, depression, pain and fatigue are not fully taken into account by the WCA.⁹ To avoid the same problems with PIP, the new assessment must be developed with these issues in mind. In addition, those who are involved in the assessment process must have specific training in HIV and the impact it may have on daily living and mobility needs.
16. The proposals do not include any explanation of how the assessment for PIP will adequately measure the real impact of fluctuating conditions like HIV. This was a serious flaw with the WCA, which is now being addressed by the second Independent (Harrington) Review.

Cuts to the budget and prioritising who should receive PIP

17. We are concerned by the stated aim to cut spending on DLA/PIP by 20%. The Government has promised to protect the "most vulnerable" and to "ensure that our resources are focused on those with the greatest need". The information that has been made available about the PIP assessment so far, that it will prioritise those with "the greatest challenges" suggests that judgements of need will be based on severity of impairment. This is at odds with the intention of DLA/PIP to take a social approach to disability, focusing on the full range of

⁸ Survey by the DBC on disability benefits- report forthcoming. Approx 150 responses from people living with HIV.

⁹ NAT. 2010. 'Unseen disability, unmet needs'. www.nat.org.uk

barriers to participation. Even those with comparatively lesser disability-related needs face extra costs to participate, and will face exclusion if they are not assisted with these. DLA meets these needs, but it seems that PIP will not.

18. For people living with HIV, DLA can have an important preventive and health-promoting affect, which could be lost if PIP is focussed only on those identified to have severe physical and mental barriers. For example, DLA can help someone with HIV manage a treatment regime which is both physically and mentally demanding, especially if they experience common HIV-related problems such as depression, fatigue and gastro-intestinal problems. DLA may help them access formal counselling, pay for travel to in informal peer-to-peer support group, or simply keep them in touch with an individual support network. Without such preventive support an individual may fail manage their condition, deteriorate physically and/or mentally, meaning they will require much more costly assistance in future.

Recommendations

19. The Committee should seek clarification on the following aspects of the provisions to abolish DLA and introduce PIP:
 - Has the Government gathered evidence on the current participation needs of disabled people and the extra costs they face?
 - What steps will be taken to ensure that the new assessment for Personal Independence Payment does not repeat the problems with the Work Capability Assessment?
20. Details of the new PIP assessment should be included in the Bill, not left to regulations. Where regulations are used, these should all be affirmative instruments.

NAT
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