Welfare Reform and Work Bill Public Bill Committee

Joint Submission from NAT (National AIDS Trust) and HIV Scotland

About NAT

NAT is the UK’s HIV policy and campaigning charity. All our work is focussed 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.

Contact: Sarah Radcliffe, Policy and Campaigns Manager, NAT
Email: sarah.radcliffe@nat.org.uk
Tel: 0207814 6767

About HIV Scotland

HIV Scotland is the national HIV policy organisation for Scotland. We exist on behalf of all those living with and at risk of HIV to ensure that Scotland has responsive policies, quality services and a supportive environment that enable people living with or at risk of HIV in Scotland to live healthy and fulfilling lives. We speak out for people living with and at risk of HIV by:

- Ensuring that the lived experience and viewpoints of people living with or at risk of HIV inform the discourse on HIV issues, health and social policy and service provision in Scotland.
- Engaging with people living with and affected by HIV to shape policy in Scotland.
- Providing information, training and resources.
- Signposting to evidence, expertise and community experience.

Contact: Aidan Collins, Head of Policy and Campaigning, HIV Scotland
Email: aidan.collins@hivscotland.com
Tel: 0131 558 3713
Summary

HIV continues to be poorly understood in the context of welfare and people living with HIV are already being disproportionately impacted by welfare reform. People living with HIV may require welfare benefits at different times and for different reasons - whether it be to stay in work, maintain their health and independence, or simply to meet their basic living needs.

Although most people living with HIV in the UK now have a normal life expectancy and good quality of life, there remain a significant minority who are chronically unwell and disempowered. Around 1 in 10 people accessing HIV care in the UK currently rely on Disability Living Allowance to manage the extra costs of living with their condition.

In particular, the complex support needs of people living with HIV who received their diagnosis in the 1980s can often go unmet. As they did not have access to effective treatment, many in this group developed serious and enduring health problems and impairments. Similarly, people who receive their HIV diagnosis late or very late can have significant support needs and may require welfare support for day-to-day living. For some people, even the smallest changes in circumstances can lead to a rapid deterioration into poverty. Furthermore, HIV is a fluctuating condition, meaning symptoms and the effects of medication can vary from day to day. This can be a real barrier to people gaining and maintaining employment and may be why they claim benefits.

HIV also remains a stigmatised condition in the UK and many people living with HIV experience direct discrimination related to their condition. Some people living with HIV experience rejection by partners, families and friends, and are therefore unable to rely on traditional support networks for help during times of trouble. This makes it even more crucial that there is appropriate welfare support for times of illness and personal financial crisis.

Our primary areas of interest in the Bill are

- The Benefit Cap (Clause 7)
- Assessing the impact of the benefit cap on disabled people (Clause 8)
- Reviewing the impact of the benefit cap annually (Clause 8)
- Freeze of certain social security benefits for four tax years (Clause 9)
- Employment and Support Allowance - Work related activity component (Clause 13)

We will be backing the amendments put forward by the Disability Benefits Consortium. NAT is a member of the Disability Benefits Consortium and is active in its policy and parliamentary working groups.

The Benefit Cap (Clause 7)

1. The lowering of the benefit cap to £23,000 in London and £20,000 outside London will have an impact on people who are unable to work due to HIV-related illness.

2. While the exemption from the cap of those in receipt of Disability Living Allowance (DLA), Personal Independence Payment (PIP) and the support component of Employment and Support Allowance (ESA) is very welcome, we do not believe this is sufficient protection for vulnerable people living with HIV who may be in receipt of other benefits.

---

1 HIV Scotland & Hepatitis Scotland, Welfare Reform in Scotland: The impact on people living with HIV and viral hepatitis, July 2014
2 7,680 DLA claimants with ‘AIDS’ listed as their main disabling condition. DWP statistics. May 2014.
3 NAT, Fluctuating symptoms of HIV, August 2011.
3. The basic rate of Employment and Support Allowance (ESA), which is the major part of the income received by those who face health-related barriers to work, is not exempt – only the additional top up received by those in the Support Group of ESA. This means that it is entirely possible that someone with HIV will have been assessed as having limited capability for work or work-related activity, and still affected by the benefit cap.

4. People living with HIV are already disproportionately affected by poverty, which can have direct impacts on their health and wellbeing. Increasingly, people living with HIV need to rely on food banks and HIV charities to even get the food they need. Nutrition is crucial to effective management of HIV. Antiretroviral drugs effectively control HIV infection, but without sufficient nutrients, the immune system cannot rebuild itself or protect itself from infections, weight loss and muscle wasting. For the first time, HIV clinicians are reporting that they must prescribe supplements to patients who cannot afford the balanced diet they need. Poverty therefore directly undermines the work of the NHS.

5. People living with HIV who are affected by the welfare reforms which have already been implemented by the previous Government have told us that the stress and anxiety of dealing with welfare changes has already had a direct effect on their physical health and their ability to manage their own care and treatment.

6. In addition, responding to the effects of welfare reform has meant that some health and social care services have been forced to divert time and resources from other vital areas of their work. Several service providers have commented to us that that as a result they are finding it more difficult to focus on their core activities supporting people in relation to their general health and wellbeing.

7. NAT and HIV Scotland support the amendment suggested by the Disability Benefits Consortium:

**Suggested amendment**
Clause 7, Page 9, line 6, at end insert new sub-clause:–

(1) Households containing members who are disabled under the Equality Act 2010 definition are exempt from the benefit cap

Assessing the impact of the benefit cap (Clause 8)

8. The impact assessment accompanying the Bill contains no detail on the possible impact on disabled people not in receipt of DLA/PIP.

9. NAT and HIV Scotland support the amendment suggested by the Disability Benefits Consortium:

**Suggested amendment**
Clause 8, page 11, line 29, at end insert new sub-clause:–

---

5 HIV Scotland & Hepatitis Scotland, Welfare Reform in Scotland: The impact on people living with HIV and viral hepatitis, July 2014
6 ibid
Before lowering the benefit cap threshold the secretary of state should assess the impact of the benefit cap on disabled people, their families and carers and report his or her findings to parliament.

Reviewing the impact of the benefit cap annually (Clause 8)

10. The annual review of the benefit cap should include explicit consideration of the impact on disabled people.

11. NAT and HIV Scotland support the suggested amendment made by the Disability Benefits Consortium:

Suggested amendment
Clause 8, page 10, line 30, at end insert new sub-clause:-
() the impact on disabled people, their families and carers, and

Freeze of certain social security benefits for four tax years (Clause 9)

12. For the reasons discussed in points 2-6 above, we very much welcome the exclusion of DLA and PIP from the four-year benefit freeze. However, we are disappointed that ESA is not also included in this exclusion.

13. NAT and HIV Scotland believe that ESA should always be considered a ‘disability benefit’. It is an income-replacement benefit for those who are currently not in work; but the ESA eligibility criteria make clear it is only for those with serious and long-lasting health problems that exclude them from the workplace. For the purposes of the freeze, therefore, it should be considered as analogous to DLA or PIP, not to jobseekers allowance.

14. Given this, we believe that including ESA in the benefits freeze does not meet the spirit of the Conservative manifesto commitment to “freeze working age benefits for two years from April 2016, with exemptions from disability and pensioner benefits” (p28).

15. NAT and HIV Scotland support the suggested amendment made by the Disability Benefits Consortium:

Suggested amendment
Clause 9, Page 11, line 33, at end insert new sub-clause:-
() People who are disabled under the Equality Act 2010 definition are exempt from the freeze

Employment and Support Allowance - Work related activity component (Clause 13)

16. Employment and Support Allowance (ESA) is only awarded to people who have been through the rigorous Work Capability Assessment (WCA) and have not been found ‘fit for work’.

17. Those who receive the Work-Related Activity Group (WRAG) component are thought to have health-related barriers to work which may reduce over time and with the right
support. There is no expectation that people living with HIV in the ESA WRAG will be able to work or will look for work.

18. Eligibility for ESA WRAG is assessed using a points-based functional assessment, whereby the claimant must reach an agreed threshold of seriousness of their impairment. The following are examples of the level of impairment which someone living with HIV must demonstrate in order to be found eligible for ESA WRAG:

- At least once a month experiences loss of control leading to extensive evacuation of the bowel and/or voiding of the bladder.
- Cannot mobilise more than 100 metres on level ground without stopping in order to avoid significant discomfort or exhaustion AND is unable to get to a specified place with which the claimant is unfamiliar without being accompanied by another person.
- The DWP decision maker assessed that there would be “substantial risk to the mental or physical health of any person if the claimant were found not to have limited capability for work.”

19. ESA is paid at a higher rate than JSA. This is appropriate, given the extra barriers to employment which people with illness and disability face, meaning they are often reliant on benefits for longer.

20. Already people living with HIV who need to claim ESA struggle to meet their essential needs. Increasingly, people living with HIV need to rely on food banks and HIV charities to even get the food they need. Reducing this already limited support will increase the health-related barriers to work experienced by people living with HIV, taking them further away from the workplace.

21. NAT and HIV Scotland support the suggested amendment made by the Disability Benefits Consortium:

Suggested amendment
Page 14, line 1
leave out Clause 13

NAT and HIV Scotland,
3 September 2015