Member Business Debate: Halt Welfare Reform
A joint briefing from HIV Scotland and NAT (National AIDS Trust)

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.

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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.

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Key Points about HIV in Scotland

HIV is considered a disability from the point of diagnosis and a protected characteristic under the Equality Act. Since the introduction of antiretroviral therapy, people living with HIV are enjoying healthier longer lives. However, people living with and at risk of HIV face a unique set of challenges that go far beyond healthcare services including issues around employment, welfare, stigma and ageing. We must understand and address the challenges that people can experience in these areas if we are to create a fairer, healthier Scotland for everyone.

Some key points about HIV in Scotland:

- 4967 people are currently diagnosed as living with HIV in Scotland (HPS until March 2015)
- The Scottish Government estimates that around 25% of people with HIV remain undiagnosed\(^1\)
- In 2014, there were 374 new diagnoses of HIV in Scotland\(^2\)
- One in four people living with a diagnosed HIV infection in the UK is now aged 50 years and over\(^3\)

HIV and welfare

HIV continues to be poorly understood in the context of welfare and people living with HIV are already being disproportionately impacted by welfare reform.\(^4\) 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.\(^5\)

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

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\(^2\) Health Protection Scotland, *HIV infection and AIDS: quarterly report* to 31 Dec 2014
\(^5\) 7,680 DLA claimants with ‘AIDS’ listed as their main disabling condition. DWP statistics. May 2014.
poverty. Furthermore, HIV is a fluctuating condition, meaning symptoms and the effects of medication can vary from day to day.\textsuperscript{6} 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.

\section*{Impact of welfare reform}

“I live with AIDS Dementia, Crohn’s Disease, and Irritable Bowel Syndrome. Stress and anxiety really affects my illness. I live hand to mouth each week financially”. – Person living with HIV

“The speed of the reforms are not allowing services, let alone individuals’ time to understand them and adjust.” – Service provider

“The migration from Incapacity Benefit was very stressful and took seven months, and I am already stressed about the PIP assessment even though that is still some time off, because it seems to be punishing the disabled by withdrawing support.” – Person living with HIV

A survey\textsuperscript{7} of people living with HIV and hepatitis, to help identify the impact of the welfare reforms in Scotland, revealed that changes to welfare being implemented at a UK level are not appropriate in a Scottish context, and not at all suitable for people living with HIV. The survey uncovered that:

\begin{itemize}
  \item 58\% described having poorer mental health
  \item 48 \% described having poorer physical health
  \item 45\% struggled to pay for gas/electricity and 39\% struggled to buy food
  \item 35\% had borrowed money
  \item 35\% could not afford to see friends and family
  \item 23\% could no longer afford to work
  \item 16\% could not afford to attend medical appointments
  \item 36\% had been affected by the under-occupancy rule
  \item 55\% did not feel there was enough information and support available
\end{itemize}

Poverty, isolation and stigma was shown to have become worse. Reforms, including the introduction of Personal Independence Payments and the under-occupancy rule, are at odds with efforts and national strategies which seek to improve the lives of people living with HIV.

People living with HIV have indicated that the pace of change of welfare reform has resulted in them being unsure of what funds they can access. The introduction of PIP has resulted in considerable concern by people living with HIV that the points based assessment process will replicate the failings of the Work Capability Assessment, particularly in its inability to

\textsuperscript{6} NAT, Fluctuating symptoms of HIV, August 2011.
\textsuperscript{7} HIV Scotland & Hepatitis Scotland, Welfare Reform in Scotland: The impact on people living with HIV and viral hepatitis, July 2014
account for fluctuating conditions. In addition, while we support measures to help people get back into work, this should not require people to be forced into unpaid inappropriate work placement schemes.

The 2015 Conservative Party manifesto pledged to lower the benefits cap to £20,000\(^8\), we believe this could have a detrimental impact on people who are unable to work because of illness or disability. Furthermore, welfare reform is impacting on the health and social care services which exist to support people to maintain their health. In our joint submission to the UK Parliament’s Welfare Reform & Work Bill Committee we highlighted that poverty directly undermines the work of the NHS\(^9\).

**A welfare system fair for all**

We support calls by the Scottish Campaign on Welfare Reform (SCoWR) for a new approach to social security in Scotland. HIV Scotland is a member of SCoWR and is active in its policy and parliamentary work. This coalition of over 40 key third sector organisations, faith groups, unions and charities from across Scotland was set up to highlight shared concerns about the UK government’s welfare reform proposals. Together we are campaigning for the following:

- **Increasing benefit rates to a level where no one is left in poverty and all have sufficient income to lead a dignified life.**
- **Making respect for human rights and dignity the cornerstone of a new approach to welfare.**
- **Radically simplifying the welfare system.**
- **Investing in the support needed to enable everyone to participate fully in society.**
- **Making welfare benefits work for Scotland.**

All of the above changes could go far to insure that people living with HIV or at risk of HIV are not disadvantaged within the welfare system and supported to live healthy and fulfilling lives. It is time for a system which prevents poverty, treats people with dignity and respect and supports everyone to flourish.

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8 Conservative Party, *2015 Manifesto*

9 NAT and HIV Scotland, *Welfare Reform and Work Bill written evidence*