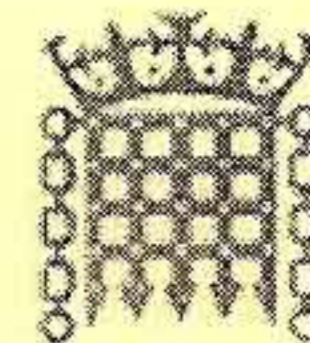


ALL-PARTY PARLIAMENTARY
GROUP ON AIDS



2nd December 2008

Dear [REDACTED]

Thank you very much for your letter and for your kind welcome to my new post.

The All Party Group passionately believes in the importance of working to improve the lives of people with HIV in the UK and to prevent new infections here. The Group divides its time roughly 50/50 between UK and international related work. In practice we always spend at least as much time on UK issues simply because of the range of Government Departments we need to deal with. You mentioned work with the Department of Work and Pensions; we are also in contact with the Department of Children Schools and Families about sex education in schools; with the Home Office on immigration and access to treatment and of course, we are in regular contact with the Department of Health.

Our international work is often events-focussed and so can be more visible, but it would be a mistake to conclude that we concentrate on international development at the expense of HIV in the UK. Both aspects of our work inform the other and having the balance, I believe, improves our ability to understand the challenges we face in both.

I know you have been in contact with Veronica about the ESA and we as a group have been working on that. You may like to see our submission to the Secretary of State for the Department of Work and Pensions consultation on their Green paper on reforming welfare to reward responsibility – I enclose a copy. We also raised the issue in parliamentary questions.

Thank you for your suggestion about looking into HIV and older people. It is an issue that Government and civil society needs to consider carefully as more and more people with HIV live to their old age. We have not pulled together our programme for 2009 yet and it will be something we will consider.

In the meantime, thank you very much for writing. Please do keep in touch with us via Veronica Oakeshott, who I know very much values your input.

Best wishes for the excellent work you do at TCell and please do encourage the people you come into contact with to get in touch with their own MPs. This in itself is an important way of keeping HIV on the political agenda.

Yours sincerely

David Borrow MP
Chair

The All Party Parliamentary Group on AIDS

Rt Hon James Purnell MP
Department for Work and Pensions
Caxton House
Tothill Street
London SW1H 9DA

22nd October 2008

Dear James,

No one written off: Green paper on reforming welfare to reward responsibility

I am writing as the Chairman of The All Party Parliamentary Group on AIDS in response to the above consultation.

The APPG recognises that the ability to contribute and participate in society, either through work or volunteering, can contribute to the health and self-esteem of individuals living with HIV. It welcomes Government measures to support those who are fit to work, physically and mentally, to do so.

However, as the Department develops its ideas on this front we urge you to bear in mind some of the special circumstances that people with HIV find themselves in, and ensure any new system is sufficiently sophisticated to reflect these.

1. HIV is a fluctuating condition

People with HIV have fluctuating health due to their compromised immune systems. Their health on the week or even month of the assessment may not represent their longer-term health. They are more susceptible to illness and may get side effects from the drugs they take to control their HIV. A person's short-term health can be worsened when they change their treatment regime – which may be necessary if they start to become resistant to their current medicines. The assessment system for benefits must take account of the fact that people living with HIV's health can vary widely between one week or month and the next.

The re-assessment of the Disability Living Allowance has not re-assured people living with HIV sufficiently on this issue. Crusaid, a charity for people living with HIV in the UK, has seen several cases of people who have stopped taking their treatment in advance of a DLA re-assessment to make sure they are more ill on the day. This is very dangerous for their long term health as it can lead to resistance to the drugs they are taking. It is not enough for the system to be flexible it must be known to be flexible by those being re-assessed.

2. HIV is a stigmatised condition

Recent research shows a third of people with HIV have suffered some form of discrimination and the National AIDS Trust has numerous examples of people who have faced discrimination at work. Although the Disability Discrimination Act should protect job applicants from this, there are always ways to not to offer someone a job. A person's ability to find a job does not just rest with them but also with employers' willingness to offer a job. The consultation looks primarily at the individual's responsibility work if they can, but it should recognise that work is a two way process and any comprehensive new system should look at how stigma in the workplace can be tackled, and invest resources in this.

It must also be recognised that as well as stigma from employees there may be *fear of stigma* amongst those being asked to work. Many people on Incapacity Benefit now will have worked once and will have had a bad experience. A common experience is breach of confidentiality. A MORI poll done for the NAT in Nov 2007 found that 44% of people would expect to be told if one of their work colleagues was HIV positive. Employers sometimes think they have a duty to tell their other staff and therefore sometimes make mistakes. In fact of course, the employer's duty is to treat any health information of their employees as confidential unless otherwise indicated by the person concerned. Personal advisers in any welfare to work type programme need to be aware of the sometimes well-founded fear of stigma that exists for people living with HIV. Above all, they need to understand that they too are bound by rules of confidentiality.

People living with HIV are faced with decision whether or not to tell their potential employers that they have the condition. When clients ask for advice about whether or not they should disclose their HIV status to a potential employer, advisers need to be able to either give legally sound advice or refer clients to someone who can.

3. HIV and Poverty are closely linked

People living with HIV are particularly vulnerable when they are living in poverty – they have compromised immune systems, the success of their treatment relies on them having a good, well balanced diet, and they need to be able to live in decent housing without fear of damp or cold. Many people living with HIV are already living in poverty and over the past year the charity crusaid, which makes hardship grants to people living with HIV, has seen a 60% increase in applications for support with food bills. Changes proposed in this green paper must not drive additional numbers of people living with HIV into poverty, even for short periods of time.

Many of these recommendations reflect our key concern, which is that at all stages, those dealing with people living with HIV, understand the impact of HIV on a person's ability, either psychologically or physically to work. This needs to include those doing the medical assessments, those giving job advice and skills training and ultimately those employing people with HIV. We cannot expect that Personal Advisers will be able to develop a detailed knowledge of HIV and other chronic illnesses *but we can expect that they are trained in the key aspects of these individual conditions*, especially as they relate to the workplace. We would certainly also expect any medical assessor to have detailed understanding of HIV. Improving knowledge of HIV and other stigmatised conditions in the workplace is a wider task, but the Government can and should play its part, and therefore tackling workplace stigma must be a long term, funded, part of this package.

Yours sincerely

David Borrow MP
Chairman
All Party Parliamentary Group on AIDS

PS. You may remember that many of these issues were raised earlier this week in the chamber at Oral PQs

cc. Welfare Reform Green Paper Team, Room 249, Level 2, The Adelphi, 1-11 John Adam Street, London, WC2N 6HT