

## The National AIDS Trust's Response to the Government Consultation: A New Deal for Welfare, Empowering People to Work



### About NAT

The National AIDS Trust (NAT) is the UK's leading independent policy and campaigning voice on HIV and AIDS. It aims to prevent the spread of HIV, ensure people living with HIV have access to treatment and care, and eradicate HIV-related stigma and discrimination.

### Summary of Recommendations

NAT calls for:

- HIV prevention to be accorded a higher priority in the Government's public health policies to prevent ill health that can lead to incapacity.
- The needs of people living with HIV to be considered in the review of the Capability Assessment process.
- Personal Advisors to be properly equipped to understand and respond to the specific needs and experiences of people living with HIV.
- The Government to abandon its unnecessary proposals for conditionality and fraud detection.
- The Government to abandon any plans that would lead to reduced benefit levels for the under 25s.
- The Government to ensure that HIV is not marginalised in its proposed initiatives with healthcare professionals.
- The Government to include HIV service providers in moves to better involve the private and public sector in enabling claimants to prepare for employment.
- The Government to do more to encourage employers to meet their obligations to enable people living with HIV to enter and remain in the workplace.

### Introduction

In January 2006, the Government launched its consultation on reform of the welfare benefits system: *A New Deal for Welfare – Empowering People to Work*.<sup>1</sup> This paper sets out NAT's response to the consultation as it relates to the needs of people living with HIV. We have focussed here on the proposals relating to Incapacity Benefit (IB) reform. However, we recognise that people living with HIV may also be lone parents and older people. Many of the responses of other organisations with expertise in these areas will apply to people living with HIV who retain membership of these groups. We have also concentrated on broader issues of policy, recognising that other organisations are better placed to comment on the detailed technicalities.

### The Needs of People Living with HIV

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<sup>1</sup> Department for Work and Pensions (2006) *A New Deal for Welfare: Empowering People to Work*. London: DWP.

There are currently around 58,300 people living with HIV in the UK, of which approximately a third are undiagnosed. The numbers of people infected continues to rise yearly.<sup>2</sup>

The majority of people living with HIV are of working age. Due to developments in HIV treatment and care, many people living with HIV enjoy productive working lives that do not require the support of the benefits system. However, it remains the case that others cannot fully benefit from the advances in medical treatment, or experience debilitating side effects (either in the short or longer-term) that can lead to periods of ill health and incapacity. As well as physical limitations, mental health problems can also manifest, related to the stresses of living with a long-term and highly stigmatised condition.

In some cases, physical and mental health problems are such that people living with HIV are unable to work and become eligible for disability benefits such as IB. The status of HIV as a disability was formalised by the Disability Discrimination Act (DDA) 2005. This stated that HIV automatically met the definition of a disability for the purposes of the Act from the point of diagnosis

It is difficult to quantify the numbers of people living with HIV in receipt of benefits. However, poverty is an increasingly documented problem. In December 2005, the charity Cruisaid, which administers an HIV hardship fund, estimated that over a third of people living with HIV in the UK had experienced extreme poverty. Cruisaid estimated that it had helped 26,346 of the 74,977 people who had been diagnosed with HIV in the UK to that period. It further reported that the average income of applicants fell from £93 to £54 per week over a five-year period.<sup>3</sup>

As well as health problems and poverty, people living with HIV may also face discrimination, which acts as a barrier to employment. This can be related to prejudice against social groups most affected by HIV in the UK, or erroneous fears about the risk of HIV transmission in the workplace. Although unlawful according to the DDA (1995, 2005), cases of discrimination in employment continue to come to light.

It is important not to paint an entirely bleak picture. Many people living with HIV will not encounter the difficulties described. However, any informed debate about welfare benefits reform as it affects people living with HIV must acknowledge these issues.

## **Welcome Proposals**

There is much to be supported in the Government's recent actions; in particular the passing of the DDA 2005. This not only clarifies the protection from discrimination afforded people living with HIV but also, through the duty to promote equality for disabled people, offers real potential to prevent discrimination from happening.

A further crucial development is the reform of the 'linking rules' announced in the 2005 Budget, so that a claimant can automatically return to the same level of benefit within a two year period if their move into employment fails. If properly administered and made known to people living with HIV receiving benefits, this would do much to allay fears about venturing back into the labour market.

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<sup>2</sup> Health Protection Agency. (2005) Mapping the Issues. HIV and other Sexually Transmitted Infections in the United Kingdom, 2005. London: Health Protection Agency Centre for Infections.

<sup>3</sup> Cruisaid (2005) Press Release: One Third of all People Diagnosed with HIV in the UK Have Experienced Extreme Poverty (30/11/2005). [http://www.crusaid.org.uk/facts\\_news\\_links/news.asp](http://www.crusaid.org.uk/facts_news_links/news.asp)

Regarding the proposed IB reforms, we welcome the underlying principles, which acknowledge that disabled people or those with long-term health conditions generally want to work. The multi-faceted extra support available through the rollout of the Pathways to Work scheme could potentially enable many of them to do so, if the successes of the pilots can be realised on a larger scale.

We also welcome the recognition that volunteering can be a vital step towards paid employment, not least within the HIV service sector itself, which has a proud history of self-help and the provision of volunteering opportunities. The proposed continuation of the right to undertake unlimited volunteering opportunities will be important in enabling people living with HIV to develop knowledge, skills and confidence in preparing for paid employment.

These are important and tangible policy initiatives that will assist people living with HIV to make the transition to employment. However, our welcome is not unqualified. There remain a number of outstanding issues of concern about the welfare benefit proposals as follows.

## **Ongoing Concerns**

### **Links With Public Health Policy**

The proposals rightly address the need to create healthy workplaces, concentrating on measures to improve occupational health and safety. While this is to be welcomed, we are concerned that broader public health initiatives need to be better aligned to support this - benefit reform must be underpinned by measures to prevent the ill health that creates need for welfare benefit. The government recognises that its policy of local devolution of healthcare is leading to the diversion of funds away from HIV prevention, while at the same time exponential increases in sexually transmitted infections and historical under investment have led to extreme pressures on sexual health services.<sup>4,5</sup> Delays in access to testing and treatment services can lead to later diagnosis, complications and onward HIV transmission.<sup>6</sup>

□ NAT calls for HIV prevention to be accorded a higher priority in national public health policy to prevent the ill health that can lead to the need for welfare benefits. This must be supported by adequate investment and proper scrutiny of devolved decision-making to ensure that HIV prevention does not become a marginalised concern.

### **Assessment for Eligibility**

We note the acknowledgement of the shortcomings of the Personal Capability Assessment and refer to the findings of the Citizen's Advice Bureaux that medical assessments are often inadequate and that mental health assessment is especially poor.<sup>7</sup> We are concerned that the needs of people living with HIV will be given

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<sup>4</sup> Department of Health (2006) United Nations General Assembly Special Session (UNGASS) On HIV/AIDS – UK Report On Progress. <http://www.dh.gov.uk/assetRoot/04/12/64/65/04126465.pdf>

<sup>5</sup> Department of Health (2004) Choosing Health. Making Healthy Choices Easier. London: DoH.

<sup>6</sup> Ibid, 2004.

<sup>7</sup> Citizen's Advice Bureaux (2006) What the Doctor Ordered. CAB Evidence on Medical Assessment for Incapacity and Disability Benefits. London: CAB.

similarly inadequate attention, either in the development of the new process, or in the administration of them.

☐ NAT calls for people living with HIV, their advocates and HIV specialists to be fully involved in the development of the new Personal Capability Assessment process.

☐ NAT calls for the new Personal Capability Assessment to be founded on a holistic and person-centered approach. This should include: a comprehensive and appropriate mental health component; proper consideration of the impact of fluctuating conditions/intermittent symptoms; and recognition of the extent to which capability is affected by wider circumstances (e.g. the availability of social and family support).

☐ NAT calls for all assessors to be trained in the needs of people living with HIV and how to administer the new process fairly and sensitively in HIV related cases. This will need to include an understanding of HIV as a fluctuating and complex condition.

### **Quality Advice and Support**

The announcement of the rollout of Pathways to Work heralds an increasingly powerful role for Personal Advisors. The success of the initial pilots was attributable in part to their skills and motivation to work with disabled people.<sup>8</sup> However, the proposals note that extra initiatives are required to develop capacity to deal with complex mental health problems. We see a similar need in relation to HIV.

To work effectively with people living with HIV, Personal Advisors need as a minimum: an understanding of the complexities of HIV as a condition and the demanding and complicated treatment regimes; an understanding of the relationship between HIV and risk of poor mental health; an awareness of the discrimination that people living with HIV can face in employment; and the ability to adhere to non-discrimination in their own practice. We are unconvinced that people living with HIV will universally receive quality support, based on sound knowledge and expertise, without the provision of specialist training for Personal Advisors.

☐ NAT calls for all Personal Advisors to be required to undergo equalities training that expressly deals with HIV related discrimination, as well as training on the specific needs and experiences of people living with the condition.

### **Conditionality**

The proposals note that most people claiming incapacity benefit wish to work and that this can be facilitated with the right support and the removal of disincentives (e.g. the fear of loss of benefits). We therefore see as misguided the approach taken to conditionality, whereby benefits are reduced for apparent non-compliance with work-related activities.

As noted, people living with HIV are especially vulnerable to poverty. The application of financial penalties for non-compliance risks plunging people living with HIV into further poverty, with no evidence that this will lead to increased compliance with work-related activities.

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<sup>8</sup> Corden, A., Nice, K. and Sainsbury, R. (2005) Research Report No 259: Incapacity Benefit Reforms Pilot: Findings From a Longitudinal Panel of Clients. London: DWP.

There is the risk that without proper training and knowledge about HIV as a condition, an inability to comply may be mistaken for unwillingness to do so. For example, without an understanding of the possible side effects of HIV medication, Personal Advisors are at risk of failing to properly account for the (in some cases) debilitating effects when assessing reasons for non-compliance.

Due to the stigmatised nature of HIV as a condition, it will be especially important to enable claimants and Personal Advisors to build supportive and trusting relationships in working towards re-entry into employment. The threat of financial penalties to be decided by Advisors can only hinder this.

It is also unclear as to how long a claimant will have to demonstrate compliance (and therefore be subject to the threat of sanction for non-compliance). What will happen to claimants who, after enthusiastic participation, are unable to re-enter employment, either because of fluctuating health, lack of local opportunity, discrimination or other reasons? There is presumably no time limit envisaged but this potentially leads to people living with HIV feeling that they must 'jump hoops' indefinitely, however unfruitful, simply to secure their income.

Finally, there is little evidence that such sanctions are necessary. The Government's own research regarding the Pathway to Work pilots showed that sanctions were applied in only 0.4% of cases.<sup>9</sup> There is no evidence that people living with HIV (or other disabled people) are 'work-shy scroungers', which is the unfortunate implication of the approach to conditionality taken.

## **Fraud**

In a related point, there is no evidence that people living with HIV (or other disabled people) are engaged in widespread fraud of the benefits system. Indeed, the Government acknowledges that only 1.2% of expenditure on IB is related to fraud and error. Yet we note the intention to institute ad hoc case review to combat fraud and to set up specialist investigative teams for this purpose. We remain unconvinced that the extra expenditure required represents an effective use of resources, which would be better spent enabling and assisting disabled people.

□ NAT calls for the Government to abandon its unnecessary and punitive conditionality proposals and special initiatives on IB fraud, which will serve only to intimidate already vulnerable people.

## **Involvement of Non-Government Providers**

We welcome the plans for increased involvement of the private and voluntary sector. In many cases, employment support initiatives already exist that share many of the principles of the proposed benefit reform. Although not a direct service provider, NAT is a partner in Ensuring Positive Futures, an initiative part funded by the European Union's Equal programme to support people living with HIV to enter training and/or employment. However, while examples of good practice exist, we are concerned that there is a lack of national expertise on employability initiatives that respond to the particular needs of people living with HIV.

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<sup>9</sup> Blyth, B. (2006) Working Paper No 26: Incapacity Benefit Reforms – Pathways to Work Performance and Analysis. London: DWP.

□ NAT calls for the Government to provide funding to enable HIV service providers to build their capacity in addressing issues of employability.

□ NAT calls for the Government, through funding incentives, to encourage established employability service providers to work in partnership with HIV organisations to incorporate their expertise.

## **Reforming Medical Services**

We welcome the Government's proposals to work with a wider range of medical professionals on issues of employability and health. We further welcome the efforts to better equip GPs for their newly defined role. However, we note the current pressures on the National Health Service and our concern that no extra resources are identified to enable medical professionals to meet their new responsibilities and to take up the new opportunities outlined (e.g. training modules etc.). It is unclear how the GP funding mechanisms will accommodate their role in Personal Capability Assessments.

Further, we welcome the recognition of the value of condition-management programmes in enabling people with long-term illnesses to move into employment. The HIV field has often led the way in the development of such programmes. We urge the Government to make resources available to sustain such interventions and to enable initiatives to share the good practice that has emerged from them.

Finally, in better equipping medical professionals to respond to issues of health and employment, we also wish to highlight the need for issues of HIV not to be overlooked in favour of more high profile concerns such as mental health and musculo-skeletal problems, simply because they are more prevalent.

□ NAT calls on the Government to provide resources as well as interventions to incentivise uptake of initiatives being proposed for medical professionals to develop skills and knowledge on the links between work and health.

□ NAT calls on the Government to do more to help sustain the range of HIV condition-management interventions and to enable them to share good practice.

□ NAT calls on the Government to take steps to ensure that issues of HIV are not overlooked in relation to the reform of medical culture and practice and that HIV specialists are involved and consulted accordingly.

## **Action With Employers**

We remain concerned that details of interventions with employers remain insubstantial. We note the threat of sanctions that are held over claimants yet there are no sanctions proposed for employers who fail to take steps to make the workplace a safe place for people living with HIV i.e. those that after more than twenty years of the HIV epidemic have failed to develop workplace policies on HIV, or failed to provide training and education for their staff to allay misplaced fears about HIV positive people, or who prefer to pay out-of-court settlements to make HIV discrimination cases 'quietly disappear' rather than tackle the discrimination itself. We note the potential of the DDA 2005 to tackle discrimination but see little evidence of a

commitment to informing people living with HIV of their rights, nor employers of their responsibilities.

We note the Government's intention to review the Investors in People standard in 2007 and to introduce Workplace Health Connect to advise small and medium-sized enterprises on creating a healthy work environment. We look forward with interest to detailed proposals on how these initiatives will be developed to enable employers to provide better and safer working environments for people living with HIV.

☐ NAT calls on the government to do more to inform people living with HIV and employers about the provisions of the DDA 2005 and their rights and responsibilities.

☐ NAT calls on the Government to ensure that an understanding of the needs and experiences of people living with HIV in the workplace inform its proposals regarding Investors in People and Workplace Health Connect.

### **Existing Claimants**

We note that the conditionality arrangements and threat of reduced benefits for non-compliance will be applied to new claimants only. However, the proposals state that benefit administrators will work 'more proactively' with existing claimants by increasing the number of mandatory work-focussed interviews and the frequency with which such claimants are assessed. However, it remains unclear as to whether sanctions in the form of reduced benefits will eventually apply to all claimants. This uncertainty can only cause confusion and concern among existing IB claimants and creates the (perhaps misleading) impression that the Government intends to extend the new arrangements to existing claimants at a later date by stealth.

☐ NAT calls on the Government to explicitly confirm that sanctions in the form of reduced benefits will not be applied to existing claimants at any point in the future.

☐ NAT calls for further consultation before any elements of the proposals are extended to existing claimants as mandatory.

### **Level of Benefits**

As noted, we have chosen not to comment here on the detailed technicalities of the proposed changes. However, we make one necessary specific reference here. We have learned from our colleagues in the Disability Alliance UK that the new benefit (Employment and Support Allowance) is to have a lower rate for under 25s, due to plans to bring this into line with the structure of Jobseekers Allowance.<sup>10</sup> This would not only lead to inequities in the system but has particular implications for people living with HIV because this population includes a number of young gay men, many of whom for various reasons cannot rely on the financial support of families.

☐ NAT calls on the Government to abandon proposals for a reduced rate for young people as regressive and unfair.

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<sup>10</sup> Disability Alliance UK (2006) Welfare Reform Green Paper – Less Money for Young Disabled People. <http://www.disabilityalliance.org/ibchange2.htm>

## **Concluding Remarks**

Overall, NAT welcomes the principles that underlie the proposed reforms: a move away from notions of incapacity to capability, a comprehensive package of support and assistance for all IB claimants in the form of the roll-out of Pathways to Work, underpinned by the legal protections of the DDA. However, we remain concerned about the ongoing criticisms of the eligibility assessment process; the unnecessary and misguided use of financial sanctions, which will serve only to make vulnerable people poorer and the lack of commensurate responsibilities for employers to do more to reduce barriers to employment for disabled people, including people living with HIV. We look forward with interest to the Government's response to the issues that NAT and others have raised and invite an ongoing dialogue to bring about a fairer, more effective and efficient welfare benefits system.