



## **The Work Capability Assessment: A Call for Evidence**

### ***Evidence from NAT (National AIDS Trust)***

NAT (National AIDS Trust) welcomes the opportunity to provide evidence to the Independent Review on the Work Capability Assessment (WCA).

NAT is the UK's leading independent policy and campaigning charity on HIV. We develop policies and campaign to halt the spread of HIV and improve the quality of life of people living with HIV. Policy and advocacy related to the needs of socially disadvantaged communities in the UK forms an important element of our work, and this includes people living with HIV who rely on benefits.

#### **HIV and disability benefits**

HIV is a disability.<sup>1</sup> Many people with HIV find that their health places no limits on their ability to work, but for others complications related to HIV create a real barrier to finding and staying in employment.

Individual experiences of living with HIV vary greatly, and there is an equally broad spectrum of ways in which HIV-related health issues may impact upon someone's ability to take up work. Some people may receive benefits on the basis of their HIV because they are in very poor health as a direct result of HIV-related illness. Others may experience less visible, fluctuating or short-term barriers such as fatigue, and the side-effects of treatment. For some living with HIV, a combination of both physical and mental health issues can interact to make employment difficult.

Between 2006 and 2009, one in six people being treated for HIV in the UK were living in poverty, and 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.<sup>2</sup>

#### **The Work Capability Assessment**

NAT welcomed the principles behind the introduction of employment and support allowance (ESA): commitment to ensure disabled people have the additional support

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<sup>1</sup> Equality Act 2010. Schedule 1, paragraph 6.

<sup>2</sup> NAT and THT. "Poverty and HIV 2006 to 2009". Forthcoming.

they need to get back into employment if they are sufficiently well to do so; and for those who aren't well enough to do so, support without compulsion to engage in any work-related activities.

However, we are concerned that the WCA is not yet correctly identifying which ESA claimants need which form of support – or which claimants are already 'fit for work'.

NAT has recently completed an initial review of the impact of the WCA on people living with HIV, drawing on the experiences of individual claimants and the HIV-specialist benefits advisers who support them. This involved surveys of individual clients, and submissions from and interviews with benefits advisers. Our research found two main sources of concern with the WCA as it stands - concerns with the design of the WCA, and concerns with how it is implemented in practice. These findings are incorporated in our response to the call for evidence below, and will shortly be published in an NAT report about the WCA.

Our response will focus on the findings which are specific to people living with HIV, but we are aware that many of our concerns have been echoed by other organisations who support people living with disabilities or illness.<sup>3</sup>

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**Sarah Radcliffe  
Policy Officer, NAT**

[www.nat.org.uk](http://www.nat.org.uk)

**Email: [sarah.radcliffe@nat.org.uk](mailto:sarah.radcliffe@nat.org.uk)  
Telephone: 020 7814 6722**

*NAT would like to acknowledge the assistance of the following organisations in collecting evidence about the experience of people living with HIV and the WCA, which has informed this submission:*

- *Citizens Advice Bureau (CAB) Camden*
- *George House Trust (GHT)*
- *Positive East*
- *Manchester Advice*
- *Terrence Higgins Trust (THT) Brighton*

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<sup>3</sup> CAB; Parkinson's Disease Society; Action for M.E; Macmillan Cancer Support; National Autistic Society

**Question 1a: How effectively does the WCA correctly identify those claimants whose condition is such that they are unable to undertake any form of work related activity (the support group?)**

Claimants will usually be found eligible for the Support Group of WCA based on a list of specific descriptors. From NAT's discussions with HIV-specialist benefits advisors, few of these descriptors are applicable to the more common physical and mental health problems faced by people living with HIV (discussed further below). The most relevant descriptors are those describing continence and limb function, as some people who are treated for HIV may experience side effects including diarrhoea and motor problems.

Some people living with HIV may also need to enter the support group due to a severely compromised immune system. To pass on these grounds, however, they currently rely on the decision-maker to correctly apply and interpret generic 'Special Circumstances' regulations (discussed below).

### **Descriptors**

NAT is concerned about the instructions given to healthcare professionals (HCPs) around scoring the descriptors. In the case of continence, for example, HCPs are given strict instructions to only give points on the limited capability for work-related activity descriptor if given sufficient medical evidence that the problem is severe enough. In our interviews with benefits advisors who help their clients make such claims it has become clear that the process of 'proving' this level of incontinence could be embarrassing or distressing for the claimant.

*"When folk come to me with the form, the first thing I ask is look into their eyes and say 'do you get the trots love?', and then they go, 'er, yeah', so I ask them to explain how often and whether they carry a bag of underwear, wet wipes, a plastic bag to take the messy keks and socks and whether it hits the floor, whether they need to wash their trainers, all that kind of stuff, and I then put that on the form, in all its glorious detail."*

- HIV-specialist benefits adviser

The reason that this benefits adviser needs to ask such questions is that her clients are unlikely to offer such personal details on a form or in a medical examination unless prompted. There is a need for HCPs to be more proactive in asking clients follow-up questions that fill in any perceived gaps in the evidence they have provided.

**Recommendation: HCPs who are interviewing or examining claimants living with HIV should anticipate the likely physical and mental descriptors of incapacity that may apply, and ask the claimant specific questions that will give them the full opportunity to explain the extent of their impairment.**

Beginning with an attitude of disbelief and placing the onus entirely on the claimant to 'prove' their claim is likely to cause them distress, and will lead to less complete evidence being provided in the interview. This can be the difference between being correctly identified for the support group, and being left with a lower level of support than is needed.

## **Special circumstances**

For others living with HIV who are unable to undertake any work related activity, eligibility to the support group is identified using the special circumstances rules (the 'non-functional descriptor'). Specifically, regulation 35(2), states that:

*A claimant who does not have limited capability for work-related activity as determined in accordance with regulation 34(1) is to be treated as having limited capability for work-related activity if—*

*(a) the claimant suffers from some specific disease or bodily or mental disablement; and*

*(b) by reasons of such disease or disablement, there would be a substantial risk to the mental or physical health of any person if the claimant were found not to have limited capability for work-related activity.*

This rule may be engaged in cases where someone's HIV is not (yet) well-managed, for example due to late diagnosis or the development of resistance to treatment. When someone living with HIV has a low CD4 count and/or a high viral load, they are more susceptible to opportunistic infections and illness. If someone in this condition went out to work or was involved in work-related activities, there is a substantial risk to their physical health.

There is an equivalent rule – regulation 29 – which can establish limited capability for work and allow a claimant entry to the Work Related Activity Group (WRAG).

Although we are raising the issue of special circumstances and immune deficiency in relation to the support group, NAT's comments in this section are equally applicable to the use of regulation 29.

One HIV-specialist benefits advisor gave the example of a client who had a CD4 count of 40 when she was refused ESA (in other words, she had a severely compromised immune system). She claimed JSA and attended the jobcentre for help to find work, where she was placed in a job as a cleaner. She became sick after only a couple of hours of work, owing to her compromised immune system. She was ill for a fortnight. When her adviser learnt about this she helped the client appeal her initial ESA decision. The appeal was successful.

In addition, NAT has learnt of people living with HIV who also have a TB diagnosis being found 'fit for work'. TB is a common co-infection with HIV. For someone to have both HIV and TB suggests not only a likelihood that their own health would be at risk if they were to engage in work-related activity, but also the health of the general public. However, NAT is aware of at least one case where special circumstances regulations to be engaged at appeal for a claimant with HIV and TB to be found eligible for the appropriate ESA group.

The reliance on appeals in cases such as these suggests that the WCA as stands is not consistently identifying people living with HIV who should be in the support group. There needs to be better application of regulations 29 and 35 in the medical assessment and decision making process, as well as the consideration of specific consideration for key HIV clinical markers in the WCA process.

## **HIV-specific indicators of limited capability**

As noted in the introduction, people living with HIV have a wide range of experiences of how HIV currently impacts upon their physical health – some will have almost no

ill-effects, others severe or recurrent poor health. For those in the second group, the previous system of assessment for incapacity benefit included a specific exemption from a medical examination where the claimant experienced “a severe and progressive immune deficiency state characterised by the occurrence of severe constitutional disease, opportunistic infections or tumour formation.”

This exemption has not been included in the special circumstances rules for ESA. The instructions to HCPs for applying regulation 35(2) do note that this regulation may be applicable where someone has “severely compromised immune function”. However, the absence of a specific exemption means that the relationship between poor immunity and risk to oneself and others is more likely to be overlooked. It is far more likely for a claimant to end up at medical assessment without having had a chance to communicate any vital information about their HIV-related health.

There is no opportunity in either the ESA50 questionnaire or in the descriptors used in the WCA to specifically provide evidence of poor health using key HIV clinical markers such as CD4 count. Claimants may provide significant indicators like their CD4 count as part of their medical evidence from their consultant, and also directly bring it into discussion during the WCA assessment. They will be encouraged to do so if they are being assisted in making their claim by an HIV-specialised benefits adviser. Regardless, they will be reliant on the HCP to record this information and its significance correctly so that it is given appropriate weight by the DWP decision-maker who decides their claim.

Although HCPs receive training in HIV, and also have available a guide to the essential medical facts and clinical indicators about HIV, there appears to be continuing ignorance about HIV among medical assessors about the significance of even basic HIV clinical markers – as demonstrated by the case of the refused claimant who went on to claim JSA with a CD4 count of 40. NAT also has concerns about the level of knowledge of HIV clinical markers among DWP decision-makers, who may overlook the connection between a low CD4 count and the special circumstances described by regulation 35.

**Recommendation: The list of special circumstances should explicitly list severely compromised immune function. HCPs and DWP decision-makers should receive instructions on the application of the regulation, including guidance on seeking and interpreting medical evidence around HIV.**

Whether the claimant is then included in the support group or WRAG would depend upon the individual circumstances and medical evidence provided.

**Question 1b: How effectively does the WCA correctly identify those claimants whose condition is such that they are currently unable to work due to illness or disability (the limited capability for work group?)**

NAT believes that the group for those with limited capability for work, the work-related activity group (WRAG), is at present not being utilised to its full potential in helping people living with HIV enter employment. The principles of the ESA model - focusing on the abilities that claimants do have and supporting their journey back to work – should lead to positive outcomes for people living with HIV who currently need to claim disability benefits. The WRAG in particular could meet the needs of many claimants who are close to work-ready, but still need personalised support in overcoming certain barriers related to their HIV.

However, the WCA currently sets too high a threshold to capture these individuals, who tend to be found 'fit for work'. This is because some of the more common physical and mental health barriers to employment faced by people living with HIV score no points under the WCA, or insufficient points to pass (see 1c for more details).

The release of official statistics around ESA revealed an unexpectedly high proportion of ESA claimants who are being found 'fit for work'. They also indicate a possible under-use of the work-related activity group (WRAG). A technical evaluation of the WCA prior to the introduction of ESA predicted that around 49% of claimants would be found eligible, and 51% would fail.<sup>4</sup> It was also anticipated that only a small proportion of claimants would enter the support group, leaving most in WRAG. The most recent statistics show only 25% of claimants whose claim is resolved end in WRAG, 10% are assigned to the support group, and 66% fail. This suggests a missed opportunity around WRAG.

ESA recipients awarded the WRAG rate are given structured support from a trained personal adviser to help them into work. The need for extra support is a common theme among people living with HIV who wish to work, but aren't quite fully job-ready at present. For example, one respondent to NAT's survey said that he needed "some support to work", because "although I have applied for jobs I never get interviews. I have ongoing memory and concentration problems and would need help with this." In order to get the extra support that WRAG would offer, though, he would need to show evidence that his memory and concentration problems were of the following severity:

**On a daily basis, forgets or loses concentration to such an extent that overall day to day life cannot be successfully managed without receiving verbal prompting, given by someone else in the person's presence - 15 points**

This statement describes a degree of impairment of memory and concentration that would make it extremely difficult to enter work without intensive and ongoing support – someone much more suited to the support group level of ESA. On the other hand, claimants who could benefit from a much lower level of help, and would be likely to enter work as a result, are found 'fit for work' and left to claim jobseeker's allowance, or no benefit at all.

In contrast to the principles behind the ESA, of support into work for those who need it, the WCA results in "all or nothing" outcomes, where evidence of **any** level of capability for work results in refusal of benefit, and the bar for support is set extremely high.

**Recommendation: The current threshold to qualify for ESA at any level reflects a degree of incapacity more suited to the support group. It should be lowered to capture those who are 3-6 months away from work readiness and most able to benefit from personalised support through WRAG.**

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<sup>4</sup> "Transformation of the Personal Capability Assessment". Technical Working Group's Phase 2 Evaluation Report. November 2007. <http://www.dwp.gov.uk/docs/tpca-1.pdf>

**Question 1c: What are the main characteristics that should identify claimants for each group, where these may differ from the current assessment?**

NAT supports the principles behind the ESA system, that people living with disability, illness and long term conditions should be supported to take up employment wherever possible, and supported unconditionally when they can't.

However, the WCA is not yet accurately and consistently identifying those claimants with HIV who would benefit from either the Support Group or the Work Related Activity Group (WRAG).

Support Group

NAT's main concerns about the identification of claimants for the Support Group have already been raised above, where we observed that key clinical markers of health relating to HIV such as are not considered by the assessment process.

**Recommendations: HCPs and DWP decision makers should explicitly consider whether someone living with HIV has a sufficiently compromised immune system to make any work-related activity a risk to their health.**

WRAG

As observed above, NAT's research shows that people with HIV who could benefit from the support provided by ESA through WRAG are found 'fit for work' because they do not pass the high threshold under the current points system. At present, many who fail the WCA apply for jobseekers allowance (JSA), which does not offer the same personalised support as ESA. Once current incapacity benefit recipients are required to also undertake the WCA, we will increasingly also see a proportion of those who fail having no other benefit to move on to, due to ineligibility for JSA.

The points system under the WCA needs to be reviewed so that those with less severe degrees of incapacity who are close to work-ready but not able to move into employment without help are still offered the tailored support they will need.

To correctly identify the support needs of people living with HIV, in particular, there needs to be better recognition of the most common physical and mental health barriers to work, which can be overcome with appropriate support. Participants in NAT's research identified the following issues which are important to them, but which they did not feel able to raise in the WCA process:

- **side-effects of treatment:** including diarrhoea, nausea and vomiting and disturbed sleep
- **depression and/or anxiety:** people living with HIV are disproportionately affected by depression and anxiety<sup>5</sup>
- **pain:** can be a result of treatment, or the impact of the virus itself.
- **fatigue:** also can be caused by either HIV, or HIV treatment.

**Recommendation: The WCA points system needs to be reviewed to better reflect the impact of side-effects of treatment, depression and anxiety, pain, and fatigue on capability for work.**

<sup>5</sup> NAT. "Psychological support for people living with HIV". July 2010. Sigma Research. 2008. "What Do You Need 2007-2008?"

**Question 2: What evidence is there to suggest that any issues with the operation of the WCA are as a result of the policy design, and what evidence is there to suggest that they are as a result of the delivery?**

NAT's research has found evidence that the current problems with the operation of the WCA are the result of both design and delivery.

Design of the WCA

The points-based system, which creates a cumulative score of entitlement based on a set of fixed criteria is built on an outdated model of disability, and is not designed to reflect some of the most common physical and mental health barriers to employment for people living with HIV.

**An outdated model of disability**

The principle behind the introduction of ESA, which was welcomed by disability organisations, was that it would provide the necessary support to help people living with disability make the most of their abilities and overcome barriers to work. The assessment process as currently designed, however, can only pick up a narrow, medically-defined set of physical and mental impairments. The points-based system provides a cumulative score based on the severity of conditions experienced by the claimant, with no reference to the social context of their disability.

Indeed, many of the tests of physical function included in the WCA are the same used for old Personal Capability Assessment (PCA) for Incapacity Benefit (IB), but with a more restrictive scoring system.<sup>6</sup> The WCA was intended as an alternative to a prevailing 'sick note culture', but still centres on the need for claimants to provide a standard 'sick note', even those with long-term conditions.<sup>7</sup>

For some claimants with HIV, it seemed that the more straightforward or visible the disability, the more likely they were considered to have genuine barriers to work.

*"The focus was very much on getting me back to work. Because I 'look' well he assumed I had no problem [with my HIV]. But when I told him about my epilepsy he took this seriously."*

-ESA claimant with HIV

This 'illness' or 'impairment' understanding of disability is the opposite of the sort of approach, based on a social model of disability, which is needed to address the full range of barriers to work for disabled people. These include discrimination in the recruitment process and at work; the unspoken or informal expectations of workplaces about employee health and behaviour; social stigma, both explicitly and internalised; individuals' current skills and actual likelihood of being employed in their existing areas of experience; and the real-world likelihood of employers accommodating for employees with special disability-related needs. For people living with HIV, these more subtle impacts of their disability on their ability to work may be even more crucial than any physical impairment related to their HIV.

<sup>6</sup> ME Association (2009). 'Bending the rules- feature on the Work Capability Assessment'.

<sup>7</sup> National Autistic Society (2009). 'Don't write me off- Make the system fair for people with autism'.

Some of these issues can be addressed through the administration of specific disability-related benefits like ESA, and others through the benefits system more broadly. The support provided by ESA under WRAG is well-positioned to address the barriers created by discrimination, the need for reasonable adjustments and the unspoken expectations of employment. In many cases the claimants who will face these problems will have physical and psychological barriers to work as well, but not of a severity to get enough points to pass the WCA. A lower points threshold for the WCA, as already suggested, would capture many more such claimants who would benefit from the support provided by ESA.

NAT is aware that some who fail the ESA and go on to claim jobseekers allowance (JSA) may receive some specialised help from Disability Benefits Adviser (DEA) on the referral of the jobcentre. However, this support is peripheral to the main benefits system, and not all who fail ESA will have access to a DEA. There is a need for the benefits system more broadly to offer services based on a social model of disability.

**Recommendation: Welfare reform should include consideration of a social model of disability. Relevant actions would include specialised support for all JSA claimants who have a disability, staff training in the social dimensions of disabilities including HIV, and specialised support for those with stigmatised conditions.**

### **Side effects of treatment**

Highly effective treatment has made it possible for people with HIV to live long, healthy lives, and remain well enough to stay in employment. However, the same treatments are also associated with a range of side-effects, which may make working difficult some or all of the time, depending on the individual. These include diarrhoea, nausea and vomiting, night sweats and difficulty sleeping, and weight loss or gain (depending on the treatment). Some may also experience more severe side-effects such as central nervous system effects and nerve damage. For some, side effects only last for a few weeks when treatment is first commenced; for others, the effects last as long as the treatment is taken.<sup>8</sup> These side-effects can put real limits on a claimant's ability to participate in work without significant support, but the more common side-effects are not likely to be picked up in the points-based WCA.

In the case of diarrhoea, for example, an employee would need to be able to access a toilet at extremely short notice. This is not just a matter of physical access to facilities but has social dimensions. In jobs which are primarily customer-focused, either face-to-face or on the telephone, it is problematic to excuse oneself at extremely short notice. If this happens often, the employee may find their position compromised. Even in positions which involve less constant interaction, employees may find it difficult to abruptly leave a meeting, particularly with external parties.

Of the most common side effects noted above, diarrhoea is the only one to be represented in the points-system.<sup>9</sup> However, to pass the WCA on these grounds alone, the claimant would have to be able to show that they:

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<sup>8</sup> Avert (2010). 'Anti-retroviral drug side-effects'. <http://www.avert.org/aids-drug-side-effects.htm>

<sup>9</sup> Nerve damage and motor function problems are less common

**At least once a month loses control of bowels so that the customer cannot control the full evacuation of the bowels - 15 points**

This would clearly not represent a typical case for most. In many cases, a more appropriate descriptor would be the one which notes the risk of the above happening if the claimant is unable to reach a toilet. This is worth only 6 points, despite the distress that is likely to be experienced by a claimant in this situation, especially if they were in an inappropriate role, less supportive workplace, or if it was a common occurrence.

Dealing with side-effects like these in the workplace may also be associated with more general personal and social unease, particularly if HIV status has not been disclosed, or is poorly understood. As noted above, however, none of these social aspects of dealing with HIV are considered by the WCA.

It is also worth noting that claimants with HIV may also be living with more than one condition requiring medication. Some of the more common co-infections experienced by people living with HIV are treated with medications that have equally bad or even worse side-effects than anti-retrovirals. The side-effects of Hepatitis C, pneumonia and syphilis treatments were all cited by participants in this study.

The impact of side-effects should not be considered an insurmountable barrier to employment. But extra support is needed, and it cannot be assumed that this will be provided by every employer. Indeed, some key aspects of support need to be provided before someone is able to start applying for work. The purpose of ESA, and WRAG in particular, is to provide the additional assistance needed to enable people living with HIV to get (back) into work – for example, dealing with fear of stigma, and how to minimise the impact of treatment side effects. However, the current points system will exclude many living with HIV from accessing this help, by declaring them 'fit for work' when it would be more accurate to describe their capability for work as 'limited'.

## **Mental health**

For many ESA claimants living with HIV, mental health issues may be as important in limiting their capacity to work as physical problems related to their HIV. Sigma Research's 2007-8 study *What do you need?* found that anxiety and depression was the most-reported source of problems in the lives of respondents in the past year.<sup>10</sup>

Problems with self-esteem issues were also cited by participants in NAT's study. This can pose a serious barrier to employment, unless proper support is provided – the sort of support that ESA provides to recipients. However, as with the other important barriers already discussed, there are no points to be scored on the WCA for these more common mental health problems. For the impact of mental health problems to be reflected in the ESA decision, the medical evidence must fit the typology of symptoms and severity outlined by the descriptors.

In one case, a claimant with HIV noted that a chief barrier to work was post-traumatic stress disorder (PTSD), linked to torture he experienced prior to seeking refuge in the UK. (A significant number of people living with HIV in the UK today came to as asylum seekers, and learned their HIV status on arrival.) He was currently unable to work due to the effects of his PTSD. To be found eligible for ESA, however, the

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<sup>10</sup> Sigma Research. 2008. *What Do You Need 2007-2008?*

medical evidence supplied by his psychiatrist had to clearly link to one of the descriptors in the WCA, those on 'memory and concentration', or 'initiating and sustaining personal action'. Benefits advisers who participated in this study noted the opaqueness of these particular descriptors, which are difficult even for mental health professionals to interpret and respond to correctly.

For example, the descriptors for initiating and sustaining personal action read:

**Activity: Initiating and sustaining personal action**

- i. **Cannot, due to cognitive impairment or a severe disorder of mood or behaviour, initiate or sustain any personal action (which means planning, organisation, problem solving, prioritising or switching tasks) - 15 points**
- ii. **Cannot, due to cognitive impairment or a severe disorder of mood or behaviour, initiate or sustain personal action without requiring daily verbal prompting given by another person in the claimant's presence – 15 points**
- iii. **Cannot, due to cognitive impairment or a severe disorder of mood or behaviour, initiate or sustain personal action without requiring verbal prompting given by another person in the claimant's presence for the majority of the time – 9 points**
- iv. **Cannot, due to cognitive impairment or a severe disorder of mood or behaviour, initiate or sustain personal action without requiring frequent verbal prompting given by another person in the claimant's presence – 6 points**
- v. **None of the above apply – 0 points**

The mental health charity Mind notes that under the WCA, there are less descriptors dealing with mental function than in the previous IB test.<sup>11</sup> This is particularly noticeable around issues associated with depression. For someone living with HIV, the impact of depression and/or anxiety, combined with fluctuating health and possible treatment side-effects, makes employment extremely challenging. However, this cumulative effect would not be reflected in the score of the WCA.

**Recommendation: The WCA points system needs to be reviewed to better reflect the impact of side-effects of treatment, depression and anxiety, pain, and fatigue on capability for work.**

Implementation of the WCA

So far only a very small proportion of claimants living with HIV who will eventually go through the WCA have done so – only those who have made new claims. However, NAT has already been made aware of significant problems with all stages of the WCA process as currently implemented.

**ESA50 form**

No one involved in NAT's study reported spending less than an hour filling out the ESA50 form, the self-administered questionnaire which is the first step in providing evidence towards an ESA claim. One participant noted that he spent four and a half

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<sup>11</sup> Mind. (2010). 'Briefing on Mind's concerns about the impact of further changes to the WCA for people with mental health problems'.

hours working on the form by himself, before then needing another three to four hours of help from a benefits adviser to complete the form.

Claimants and their advisers both expressed having difficulties with the language used on the form, particularly, noting that the meaning was sometimes unclear, and it was also hard to understand the instructions the form gave.

As noted above, there are no HIV-specific questions, and very limited opportunity to record HIV-related physical and mental health problems within the descriptors – this was another major source of frustration for those filling in the form.

### **The face-to-face medical assessment**

The most fundamental source of frustration for claimants who undergo the WCA process is not having the opportunity to fully explain to the HCP how their condition limits their ability to take up work. This has been observed by all disability organisations who have reviewed the impact of the WCA to date.<sup>12</sup>

The simplest explanation for this common problem would be that HCPs are instructed to only receive the necessary information to respond to the closed questions in the descriptor list. However, the DWP guide to the WCA notes that the HCP will take into account other factors not covered by the descriptors, such as pain and fatigue. It also states that "the customer will have an opportunity to give any other information relevant to their assessment", and that the HCP "will consider all the information and exercise clinical judgement to reach an opinion on the nature and severity of the effects of the disabling condition."<sup>13</sup>

Participants in NAT's study indicated that this guidance is not always followed, and this is consistent with the growing evidence base collected by other disability organisations that some HCPs refuse to hear the additional information relevant to a claimant's case, and may be brusque, intimidating or simply rude in doing so.<sup>14</sup> Claimants report the HCP simply holding their hand up to stop them from talking.<sup>15</sup> As well as severely limiting the effectiveness of the assessment, this behaviour can be very upsetting for the claimant.

It also clearly contradicts the professional standards of Jobcentre Plus, to which HCPs are also expected to adhere. These include the requirement to:

- "make customers feel welcome and at ease";
- "allow the customer enough time to talk about their medical condition"; and
- "answer any reasonable questions."

By contrast, one of the survey respondents in NAT's study noted that "I felt the medical examiner was trying to trip me up."

For a claimant living with HIV, who may be trying to explain issues relating to their mental health, or side-effects of their treatment, a dismissive attitude is likely to lead

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<sup>12</sup> Parkinson's Disease Society; Action for M.E; Macmillan Cancer Support; CAB; Disability Benefits Consortium; National Autistic Society

<sup>13</sup> DWP. (2008). p13

<sup>14</sup> Evidence submitted to the House of Commons Work and Pensions Committee, 'Decision making and appeals in the benefits system'. Second report of Session 2009-2010.

<sup>15</sup> Parkinson's Disease Society. (2009). "Of little benefit and not working: People with Parkinson's experience of Employment and Support Allowance". October 2009.

them to disengage with the benefit assessment process, including the pursuit of their right to an explanation or appeal of any decision. Many will have had bad experiences discussing their HIV in other settings, but would expect that in a medical setting their health problems would be heard professionally and acted on appropriately. The actions of some HCPs clearly do not show this professionalism.

**Recommendation: There should be unannounced spot checks or mystery shopper exercises of medical examinations to ensure that HCPs consistently follow all applicable assessment guidelines and professional standards.**

### **The weight of evidence**

*"I didn't feel the examination was conducted by a competent, HIV-aware medical professional. I presented documents from [my hospital HIV clinic] relating to HIV. Side-effects of medication which I suffered from. Anxiety, stress, lethargy. She seemed unaware and generally not very empathetic."*

- ESA claimant

Even if the claimant does not have the opportunity to fully explain how living with HIV affects their ability to work to the HCP, it would be expected that the evidence provided by their doctor will fill in these gaps in information when the DWP decision maker decides their claim. According to DWP's guide, the decision maker will "carefully consider all the evidence", including "the completed customer questionnaire, the information provided by their doctor and the advice of the approved healthcare professional".<sup>16</sup>

However, a common theme in reviews of the WCA process by disability organisations is that, despite the weight of knowledge and experience clearly lying with the specialist clinician who is expert in the condition, the weight of evidence in the decision comes from the generalist HCP, who may have absolutely no specialist training in the condition.<sup>17</sup>

An adviser who contributed evidence to NAT's research noted a case which had gone to appeal, in which the claimant's side-effects from HIV treatment were a key source of difficulty in finding or staying in work. The HCP present at the hearing responded that, as the claimant's CD4 count was at an acceptable level, "why don't they just stop taking [the ARVs]?"<sup>18</sup> The claimant's HIV-specialist benefits adviser tried to explain the serious health consequences of interrupting treatment, until the judge told her to "please be quiet." As the HCP was a doctor, the judge took his opinion over that of the benefits adviser. The case was eventually found in the claimant's favour at a higher tier appeal hearing.

**Recommendation: Staff who carry out face-to-face medicals, and DWP staff who make decisions on applications, should be trained to a standard competence level in HIV and its impact.**

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<sup>16</sup> DWP. (2008). p15

<sup>17</sup> See CAB (2010); Parkinson's Disease Society (2009)

<sup>18</sup> It is vital that an ARV treatment regime, once commenced, is not interrupted. Anything less than perfect adherence to treatment 95% of the time presents a real risk of the patient developing resistance to that treatment regime. Once resistance is developed, treatment options are limited, compromising the patient's health in future.

**Recommendation: All HCPs and DWP decision-makers should be tested on basic knowledge of HIV and its impact on employment prior to carrying out any medical examinations or deciding any ESA claims.**

### **Administration and communication**

Despite the fundamental problems with the design of the WCA as discussed, and serious suggestions of poor judgements being made by the HCPs carrying out the WCA, some of the most severe impacts upon people living with HIV who apply for ESA have been the consequences of far more routine administrative and communication failures. The WCA is complex and any delay in the process, or failure in transparency or accuracy on the part of those responsible for communicating the rules, can materially disadvantage a claimant.

One benefits adviser gave the example of a client who had decided that, on balance, she was “fit for work within limits” and therefore applied for jobseeker’s allowance (JSA) rather than ESA. When she went to the Jobcentre to look for part-time work, and explained the limits HIV might place on her ability to take certain positions, she was instructed to apply for ESA instead. She failed the WCA, and had to go right back to the beginning of the JSA application process.

Even without such confusion being caused, many claimants experience delays in their claim being processed and decided. In one extreme example, a claim was delayed so much that when it was finally resolved the claimant received over £700 in arrears. In the meantime, the claimant had to rely on friends and family, and cash payments from the HIV charity Crusaid to survive.

However, even much smaller delays can make life difficult. Even though the first payment of basic-rate should be made less than two weeks after the claim is lodged, waits of at least one month were reported by NAT’s research participants. There can also be a long wait for a medical assessment - sometimes months. Delays are also often experienced at the end of the process, when successful claimants are assigned to either the WRAG or the support group. Communication of this decision is also poor; a recurring theme in NAT’s research is claimants, and even sometimes their specialist advisers, being unsure as to what rate of ESA they are actually being paid (especially when other benefits are also being received).

Other administrative problems that people living with HIV have faced in the ESA application process include:

- Clients who are still eligible under the old rules for IB and Income Support being wrongly advised by the DWP to make a claim for ESA.
- Misleading or contradictory letters concerning ESA entitlement.
- Lack of clarity in communications from DWP about the difference between contribution-based and income-based ESA, one of the most complex and difficult to understand aspects of the system.
- Claims being lost and untraceable.
- Confusion between different arms of the DWP about the progress of a particular claim.

**Recommendation: As recommended by the House of Commons Work and Pensions Committee, the Secretary of State should report on DWP decision-**

**making standards annually. These reports should be used as a basis for improving decision-making within DWP.**

**Recommendation: The migration from incapacity benefit to ESA should be delayed until systemic problems with the administration, communication and decision-making processes at DWP are addressed, and there is evidence that DWP and Jobcentres have sufficient capacity to correctly administer ESA.**

## **Appeal and review**

Since its introduction in October 2008, ESA has become the most-appealed benefit, with a 40% success rate.<sup>19</sup> It is of course appropriate that those who believe that their claim has been unfairly judged, or that all the relevant evidence has not been taken into account, appeal their decision. However, in the case of ESA it appears that the formal appeals process is sometimes used, out of necessity, in lieu of a thorough initial assessment, drawing on all relevant evidence.

Reviewing the outcomes of some appeals involving people living with HIV, it appears as if the appeal hearing ends up becoming a de facto second, and often more comprehensive and accurate, medical assessment. The official statistics show that 19.5% of successful WRAG claims were the result of an appeal, compared to 0.5% where the decision-maker applied the special circumstances rules (regulations 29 and 35) or deferred the WCA for medical reasons. In only 0.3% of cases the claimant was awarded the WRAG rate of ESA because a DWP decision-maker decided against the recommendation of the HCP.<sup>20</sup>

If a claimant wishes to challenge their decision, they can either ask for a revision (the DWP decision maker will look at the case again, including any compelling new evidence) or an appeal at an independent tribunal. However, these options may not be equally attractive. If the claimant asks for a revision, s/he will not continue to receive the assessment phase level of ESA (if s/he has not been awarded the main phase rate) in the meantime. If s/he lodges an appeal, however, benefit payments will continue until the outcome of the appeal.

The uptake of appeal mechanisms also suggests that at the decision-making stage opportunities to clarify questions about a case prior to refusal are often overlooked. For example, one benefits adviser noted that while some decision-makers do use the contact details she provides on a claim and call to ask about any aspects of the claim which are not clear, this is now the exception rather than the rule, as it has been in the past.

The comments made by participants in NAT's research also indicate that the popularity of appeals in the ESA system may reflect a fundamental lack of

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<sup>19</sup> DWP. *Employment Support Allowance: Work Capability Assessment Statistical Release*. July 2010. [http://research.dwp.gov.uk/asd/workingage/esa\\_wca/esa\\_wca\\_27072010.pdf?x=1](http://research.dwp.gov.uk/asd/workingage/esa_wca/esa_wca_27072010.pdf?x=1); BBC. 2010. "New benefits system labelled unfit". 25 March. <http://www.bbc.co.uk/news/10159717>

<sup>20</sup> Equivalent breakdowns of decision outcomes from appeal and medical reasons are not available for the Support Group. DWP. "Employment and Support Allowance: Work Capability Assessment by Health Condition and Functional Impairment". August 2010. [http://research.dwp.gov.uk/asd/workingage/esa\\_wca/WCA\\_by\\_Health\\_Condition\\_and\\_Functional\\_Impairment.pdf](http://research.dwp.gov.uk/asd/workingage/esa_wca/WCA_by_Health_Condition_and_Functional_Impairment.pdf)

transparency in the decision-making system. One benefits adviser noted that when he contacted the DWP via phone about a decision, he was unable to get an explanation about why the claim had been refused. This lack of information is far more likely to lead to appeal, which he may not have considered necessary if given the reasons for the decision.

When many feel their WCA is conducted or recorded unfairly, and they are unable to find out why they failed, confidence in the decision-making system will suffer. This will inevitably lead to even more appeals, at greater financial cost to DWP and personal cost to the individuals going through them. An HIV-specialist benefits adviser observed that as of August 2010, appeal hearings were already booked ahead until December. It can only be imagined how more overloaded this system will become, once current IB recipients begin their migration to ESA.

**Recommendation: DWP decision-makers' performance should be evaluated and rewarded for making accurate decisions the first time around, including seeking further information from claimants, their advisers and doctors where appropriate. Decisions overturned at appeal should be reviewed internally to identify trends in decision-making errors.**

**Recommendation: Claimants who seek a revision of their refused ESA claim should continue to receive the assessment rate of ESA. This would reduce reliance on the appeals system by eliminating the disincentive against seeking a revision in the first instance.**

### **Impact on claimants and HIV services**

*“The introduction of ESA and the push for people in receipt of sickness benefits to return to work means that we are increasingly receiving calls from clients who are worried about their entitlement and are feeling anxious that they will be asked to return to work when they are not ready - for instance because their condition varies so much and/or they have not worked for some time. We should not underestimate the effect this has on HIV positive claimants’ ability cope with their medication, and their general wellbeing.”*

- HIV-specialist benefits adviser

Advisers who help people living with HIV through the ESA application process are concerned about the impact that the assessment may have on their health. Their clients have applied for ESA precisely because they did not feel able to go into work, or move towards work without help and support. The WCA process and other requirements to prove eligibility for disability-based benefits in many cases only adds to the existing physical and mental health problems experienced by people living with HIV.

As the adviser notes in the quote above, the pressure can also exacerbate problems such as anxiety and stress associated with managing HIV. HIV treatment regimens have become much less onerous over time, but still need to be adhered to strictly. Timing is extremely important, and sometimes there are additional requirements to take medication with food, or store it in a certain way. There are also a range of lifestyle factors such as rest, exercise and nutrition which are important in achieving the best possible impact of the medication. Adherence to HIV treatment is challenging at any time, and the added pressure of a complex application process

which is often characterised by delays and a culture of disbelief, can make it even harder. There can be serious consequences of less than perfect adherence, which can harm an individual's health in the short-term, and lead to drug resistance in the long-term.

Other disability organisations have also given examples of clients whose health has deteriorated as a direct result of the impact of the ESA application process, including claimants with cancer, and serious mental health problems.<sup>21</sup>

Another common experience among disability organisations, including those providing support to people living with HIV, is the additional burden on services which the WCA has created. Citizens Advice bureaux throughout the UK have experienced a 50% increase in bureaux inquiries related to the administration of ESA, compared to IB.<sup>22</sup>

**Question 3: What is the best way to ensure that the effect of fluctuating conditions is reflected in the recommendation of the WCA?**

Fluctuating health is one of the main barriers people living with HIV experience in finding and retaining employment. Periods of poor health may be directly related to their HIV, to the impact of a new treatment regime, or to an infection to which their HIV has made them particularly susceptible.

The DWP guide to the WCA states that the Healthcare Professional (HCP) will take "full account of factors such as pain, fatigue, stress and the possible variability of the condition".<sup>23</sup> However, nowhere in the descriptors are occasional, or more generalised, pain and fatigue reflected. As it is not possible to pass the WCA without sufficient points, there is no way in which these issues, which particularly affect people living with HIV, could influence a claimant's ESA assessment. This was the case of one participant in NAT's study, who felt unable to work at all due to HIV-related fatigue; but was found fit for work.

The ESA Handbook given to HCPs as states that the HCP should consider how the illness or disability would impact upon the claimant's ability to work "the majority of the time".<sup>24</sup> However, even if someone's ability to work is significantly affected a minority of the time, this will still seriously impact upon their ability to find and stay in employment. There is also a great difference between sporadic and short-lived episodes of poor health and periods of incapacity which occur rarely but are long-lasting. With appropriate support, neither should exclude anyone from employment, but it is unlikely this support will be offered to those found 'fit for work' based on their health the majority of the time.

One participant in the study, who noted that her main barriers to work were side effects of treatment, fatigue, and managing pain, said that when she tried to given a

<sup>21</sup> CAB (2010); Macmillan Cancer Support. (2009). "Failed by the system".

<sup>22</sup> CAB (2009).

<sup>23</sup> DWP. (2008). 'A guide to Employment and Support Allowance- The Work Capability Assessment'. ESA214.

<sup>24</sup> Atos Medical Services (2009). 'ESA Handbook'. Version 4.

full picture of the daily impact of these factors, "the doctor minimised what I tried to say and concluded I can manage activities".

NAT's findings suggest that fluctuating conditions will not be properly reflected in WCA decisions until the symptoms experienced count under the points system. A condition that meets a descriptor, but only a minority of the time, should still accrue a proportion of the points that would be accrued if the claimant experienced limited capability the majority of the time. The claimant should receive in the range of 50-75% of the points they would if they did not have a fluctuating condition. The impact of variability on employment prospects is not limited to the days when the condition flares up. For this reason there could also be a set number of points for each regular cause of fluctuating health which satisfies a descriptor.

**Recommendation: When capability for work varies over time due to a fluctuating condition, the claimant should receive a proportion of the usual WCA points for the descriptors that apply on the 'bad days'.**

**Question 4: What is the best way to ensure that the effect of multiple conditions is reflected in the recommendation of the WCA? Are there specific conditions that should be regarded as contributing to or adding additional weight to others, where both are present?**

DWP expressed concern that the previous personal capability assessment (PCA) for incapacity benefit (IB) allowed some "double-counting", where multiple descriptors appeared to measure the same activity (in particular some around mental health).<sup>25</sup> But the points system introduced in response to this through the WCA has an opposite problem: it is possible to be considered to have real problems with two completely distinct types of activity and still not pass the WCA. For example, each of the following descriptors attracts 6 points:

**Risks 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**

**Cannot walk more than 200 metres on level ground without stopping or severe discomfort**

If these two descriptors both applied, the claimant would be found 'fit for work', despite having two significant barriers to finding work. Multiple conditions particularly impact upon people living with HIV, as the virus, because of its effect on the immune response can affect many different aspects of the physical system. In some cases, as in the above example, two impairments interact directly so that one exacerbates the impact of the other.

More broadly, though, simply experiencing two conditions that limit capability for work simultaneously means that the sum of their impact will be greater than suggested by the cumulative score under the WCA. For example, someone living with HIV who had a mental health problem in addition to one of the impairments listed above would find this creates an additional burden even if there isn't a direct interaction between

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<sup>25</sup> "Transformation of the Personal Capability Assessment". Technical Working Group's Phase 2 Evaluation Report. November 2007. <http://www.dwp.gov.uk/docs/tpca-1.pdf>

the conditions. The impact in limiting their chances of entering employment is more than the simple sum total of points would suggest.

Given this, the fairest way forward is not to identify a list of combinations of conditions where one or other adds specific weight to the other. Rather, it should be possible to pass the WCA based on the experience of any combination of multiple conditions. This means that there needs to be a change in the points system – by increasing the amount that the lower-scoring descriptors attract, and/or reducing the threshold to pass the WCA (see also the discussion of the under-use of WRAG, above).

**Recommendation: The points system should be changed so that anyone who scores points on two separate descriptors would pass the WCA.**

In addition to the points currently available for each of the activities described in the descriptors, there is a need to reflect the impact of other conditions which are not currently measured. In particular, there needs to be a means of accounting for depression and anxiety. Either some descriptors about these mental health barriers should be added to the WCA, or there should be a set amount of points added where a claimant is experiencing either depression or anxiety and this is creating a barrier to them finding work.

Setting a standard number of points (e.g. 3-4 points) would not compromise the integrity of the descriptor system as it would not be possible to pass on these few points alone, but it would more accurately reflect the impact that depression and anxiety have when the claimant is also dealing with another disability or illness. Medical evidence about their mental health would need to be provided to support these points being awarded, as with the descriptors.

**Recommendation: There should be a set number of points added to the scores of claimants who face barriers to work due to depression or anxiety.**

**Question 5: What is the best way to give adequate weighting to additional (or initial) evidence outside of that gathered through the WCA? How can any changes be achieved without placing a burden on GPs and health care professionals, and without compromising their relationship with their patients?**

NAT agrees that the medical evidence requirements for establishing ESA eligibility should not create an additional burden placed for GPs and other clinicians. However, this evidence does need to play a more substantive role in the ESA decision-making process. It is striking that medical evidence has been decisive in the majority of successful ESA appeals that NAT has become aware of. In some cases, this has involved the consideration of additional medical evidence. In others, it has meant fresh consideration of the initial evidence, because this evidence did not obviously fit the existing list of descriptors.

It is clearly wasteful to have to rely on the appeals process for proper consideration of medical evidence. Although in some complex cases additional information may need to be sought from doctors to support a claim, in many more there is sufficient evidence already provided – but it needs to be better used in the decision-making process.

NAT's research has found that at present, the interpretation of medical evidence in light of the ESA claim is extremely narrow. We have heard of cases taken to appeal where evidence from doctors has been discounted because it did not explicitly and directly address one of the activities covered by the WCA descriptors. In one case a psychiatrist had to make multiple representations about a patient's Post Traumatic Stress Disorder before it was finally accepted at appeal as evidence of incapacity for work – this is clearly an additional burden on the doctor.

Instead of placing the onus on the doctor to present evidence in a format which precisely mirrors the WCA, HCPs and DWP decision-makers should interpret the evidence and proactively apply it to any relevant descriptors. In practice, this would mean:

- If medical evidence is provided prior to the face-to-face assessment, it should be considered for any applicable exemptions from the assessment. If the evidence suggests special circumstances rules may apply (regulations 29 or 35), this should be noted.
- At the face-to-face assessment, the HCP should discuss any medical evidence which has been provided and ask for clarification of anything that isn't clear.
- HCPs should draw upon their own medical knowledge and the training materials they are provided with to explain in their notes the relevance of medical evidence to any applicable descriptors, for the information of the DWP decision-maker.
- DWP decision-makers should ask the HCP to explain any aspect of the medical evidence which is not clear.
- When the relevance of specialist medical evidence is not clear (e.g. due to its technical nature) even after liaising with HCPs, DWP decision-makers should approach the doctor for clarification.

Taking these steps will reduce the reliance on mechanisms of appeal and review. Requiring HCPs to interpret the relevance of evidence provided by HIV specialist clinicians will also raise their overall awareness of HIV and work and the accuracy of their judgements (including the application of special circumstances regulations).

Notwithstanding this, treatment of HIV is complex, and is a field of medicine subject to frequent change based on new research. Specialist clinicians are expert in both their individual patient's circumstances and the field as a whole. Where their evidence about the impact of HIV-related health problems clashes with that of the generalist HCP, the specialist views should be given greater weight by the DWP decision-maker.

**Recommendation: Medical evidence provided by the claimant's doctor concerning work capability should be considered in the decision even if it does not refer explicitly to one of the existing descriptors. If it is not clear if the evidence satisfies the WCA criteria, HCPs and DWP decision-makers should follow-up with the doctor or another specialist clinician.**

**Question 6: Is there any evidence to show that there have been particular problems with the WCA for any specific groups? These groups may include, but are not limited to, men and women, people from black and minority ethnic backgrounds, or people from differing age groups.**

NAT is aware that as with many mainstream benefits, the application process for ESA can be particularly problematic for refugees who have recently been granted leave to remain in the UK. Asylum support is withdrawn 28 days after an asylum claim has been resolved. As has already been observed, however, delays in receiving initial payments for an ESA application can be two or three months late. Such delays affect all claimants. However, refugees who have relied on asylum support are particularly likely to have no savings or other means of financial support while they wait for their benefits. They have not been permitted to work while awaiting an asylum decision and asylum cash payments are only 55% of income support. As asylum seekers and refugees are disproportionately affected by both HIV and poverty, NAT is concerned about how the administration of ESA is affecting this group particularly.

In addition, what has also become clear from NAT's research is that any ESA claimant who is not accessing specific help from a specialist benefits adviser is going to be disadvantaged. The system is extremely complicated, and someone with a detailed understanding of the rules is far more likely to be successful in an application or appeal. With limited opportunities for receiving good benefits advice and application help, many have to navigate the process themselves. This will be especially the case once the migration from IB to ESA commences, and demand for advice services rises further.

**Question 7: Do you have any suggestions for how the WCA process could be improved to better assign people with health conditions to the most appropriate part of the benefits system?**

NAT congratulates DWP on seeking this independent review of the WCA. We hope that all the evidence and recommendations made are considered fully, even if submissions indicate that fundamental changes to the process are needed. We are particularly concerned that the changes to the WCA recommended by an internal review will be made, and migration pilots will be commenced, prior to the findings of the independent review. These changes should be delayed until the findings of the review.

**Recommendation: The migration from incapacity benefit to ESA should not commence prior to the release, consideration and DWP action on the findings of the independent review of the WCA.**

**Recommendation: The new WCA rules, recommended by the internal review of the WCA, should not be finalised or implemented prior to the release, consideration and DWP action on findings of the independent review of the WCA.**

Throughout our response, we have identified specific areas in which the WCA could be improved to better identify people who are not yet ready to go (back) into work due to physical and/or mental impairment.

However, there are many more people living with disability, illness or long-term health conditions who do not face any health-related barriers to work, such as can be measured by the WCA. They will not be found eligible for disability-related benefits (ESA). However, many will still need specialist disability support in order to find employment. Given current levels of unemployment, and the upcoming migration from IB to ESA, in which many current recipients will be found ineligible under the WCA, we can expect dramatic increases in claimants with disability support needs accessing mainstream benefits such as JSA.

Any positive changes to WCA will only improve outcomes for those who meet a medical threshold of disability-related incapacity. These changes are needed, but there needs to also be reform of the support offered to all other benefits recipients, in acknowledgement of the social barriers to employment associated with disability.

In the case of HIV, stigma is still a day-to-day issue, and while many employers are proactive in creating a stigma-free workplace, this is not the case for all. And while it is unlawful to discriminate against someone in recruitment or the workplace on the basis of their HIV, they can still face more subtle barriers, as described earlier – those based on informal and unspoken expectations about employee behaviour, flexibility and attendance (including sick leave). People living with HIV may also face real barriers of confidence and self-esteem due to past experiences, or fear of stigma in the future.

These barriers can be overcome with specialised support and help, but NAT is concerned that such support will not be available to the many disabled people who are found ineligible disability benefits. As such, as well as reforming the WCA, there needs to be fundamental improvements to the way that disability is approached in all areas of the benefits system.

**Recommendation: Welfare reform should include consideration of a social model of disability. Relevant actions would include specialised support for JSA claimants who have a disability, staff training in the social dimensions of disabilities including HIV, and specialised support for those with stigmatised conditions.**

## **Recommendations**

### **The design of the WCA**

- a. The list of special circumstances should explicitly list severely compromised immune function. HCPs and DWP decision-makers should receive instructions on the application of the regulation, including guidance on seeking and interpreting medical evidence around HIV.
- b. The current threshold to qualify for ESA at any level reflects a degree of incapacity more suited to the support group. It should be lowered to capture those who are 3-6 months away from work readiness and most able to benefit from personalised support through WRAG.
- c. The WCA points system needs to be reviewed to better reflect the impact of side-effects of treatment, depression and anxiety, pain, and fatigue on capability for work.
- d. When capability for work varies over time due to a fluctuating condition, the claimant should receive a proportion of the usual WCA points for the descriptors that apply on the 'bad days'.
- e. The points system should be changed so that anyone who scores points on two separate descriptors would pass the WCA.
- f. There should be a set number of points added to the scores of claimants who face barriers to work due to depression or anxiety.

### **Implementation of the WCA**

- g. HCPs who are interviewing or examining claimants living with HIV should anticipate the likely physical and mental descriptors of incapacity that may apply, and ask the claimant specific questions that will give them the full opportunity to explain the extent of their impairment.
- h. HCPs and DWP decision makers should explicitly consider whether someone living with HIV has a sufficiently compromised immune system to make any work-related activity a risk to their health.
- i. There should be unannounced spot checks or mystery shopper exercises of medical examinations to ensure that HCPs consistently follow all applicable assessment guidelines and professional standards.
- j. Staff who carry out face-to-face medicals, and DWP staff who make decisions on applications, should be trained to a standard competence level in HIV and its impact.
- k. All HCPs and DWP decision-makers should be tested on basic knowledge of HIV and its impact on employment prior to carrying out any medical examinations or deciding any ESA claims.

- l. DWP decision-makers should consider all the evidence when making a decision, and give appropriate weight to the medical evidence provided by specialist clinicians. Where specialists in a condition contradict the notes of an Atos healthcare professional (HCP), the decision-maker should seek further information and in appropriate cases, decide against the recommendations of the HCP.
- m. Medical evidence provided by the claimant's doctor concerning work capability should be considered in the decision even if it does not refer explicitly to one of the existing descriptors. If it is not clear if the evidence satisfies the WCA criteria, HCPs and DWP decision-makers should follow-up with the doctor or another specialist clinician.

### **Administration, communication and decision-making standards**

- n. As recommended by the House of Commons Work and Pensions Committee, the Secretary of State should report on DWP decision-making standards annually. These reports should be used as a basis for improving decision-making within DWP.
- o. The migration from incapacity benefit to ESA should be delayed until systemic problems with the administration, communication and decision-making processes at DWP are addressed, and there is evidence that DWP and Jobcentres have sufficient capacity to correctly administer ESA.
- p. DWP decision-makers' performance should be evaluated and rewarded for making accurate decisions the first time around, including seeking further information from claimants, their advisers and doctors where appropriate. Decisions overturned at appeal should be reviewed internally to identify trends in decision-making errors.
- q. Claimants who seek a revision of their refused ESA claim should continue to receive the assessment rate of ESA. This would reduce reliance on the appeals system by eliminating the disincentive against seeking a revision in the first instance.

### **The WCA and welfare reform**

- r. Welfare reform should include consideration of a social model of disability. Relevant actions would include specialised support for all JSA claimants who have a disability, staff training in the social dimensions of disabilities including HIV, and specialised support for those with stigmatised conditions.
- s. The migration from incapacity benefit to ESA should not commence prior to the release, consideration and DWP action on the findings of the independent review of the WCA.
- t. The new WCA rules, recommended by the internal review of the WCA, should not be finalised or implemented prior to the release, consideration and DWP action on findings of the independent review of the WCA.