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Unseen disability, Unmet needs

A review of the impact of
Work Capability Assessment
on people living with HIV

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Executive summary

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HIV is a disability, and some people living with HIV will need to claim disability-related benefits, including employment and support allowance (ESA). To be found eligible for ESA, claimants need to pass a work capability assessment (WCA), which allocates points based on the degree to which the claimant's ability to work is limited by illness or disability.

NAT undertook 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. 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.

In respect of the design of the assessment:

- The WCA does not take into consideration key HIV clinical markers, such as CD4 count, in making the medical assessment.
- The WCA points system does not fully reflect the impact that
 - fluctuating symptoms;
 - pain;
 - fatigue;
 - side-effects of HIV treatment; and
 - depression and anxiety

have on capacity for work.

- The WCA is not based on a social model of disability, which is essential for accurately judging barriers to employment among people living with HIV.

Acknowledgements

In respect of the implementation of the assessment:

- Claimants and their advisers find the ESA50 claim form difficult to understand, difficult to fill out accurately, and extremely time-consuming.
- The medical examination is often a stressful or frustrating process. Claimants do not always have the opportunity to discuss the important issues around their physical and mental health that limit their capability for work.
- When deciding ESA claims, DWP decision-makers often give greater weight to the opinion of the Atos healthcare professional making the assessment than to HIV clinicians and other specialists who have provided medical evidence.
- Many who would benefit from receiving support to get back into work via the Work Related Activity Group level of ESA are being found 'fit for work' and refused ESA.
- A wide range of problems with administration and communication of the ESA assessment process materially disadvantage claimants.
- The ESA application process impacts negatively on the health of claimants living with HIV. The stress and pressure of the WCA affects the ability of claimants to effectively manage their HIV treatment.

Many of these findings have been echoed in the research of other disability organisations.

Based on this research, NAT makes policy recommendations around ESA, and the WCA, to improve outcomes for claimants living with HIV.

**Citizen's Advice Bureau
(Camden)
George House Trust
Manchester Advice
Positive East
Terrence Higgins Trust
(Brighton & Hove)**

HIV and disability benefits

Why the WCA is relevant to people living with HIV

HIV is a disability. 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 disability 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.

The work capability assessment (WCA)

In October 2008, employment and support allowance (ESA) was introduced to replace incapacity benefit (IB) and incapacity-based income support (IS) as the primary income support benefit for people who are unable to work due to disability or illness.

Entitlement to ESA is assessed using a new test, the work capability assessment (WCA). The WCA aims to identify claimants who have "limited capability for work" or "limited capability for work-related activity", so that they may receive the right support to help them live well and (where appropriate) return to work. Those who are found "fit for work" are not entitled to receive ESA, but may be advised to apply for jobseeker's allowance (JSA).

From October 2008, all new applicants had to apply for ESA rather than IB but to date, people who were already receiving IB prior to the introduction of ESA have continued to receive their benefits as usual. However, as of October 2010 DWP will commence a 'migration' pilot of 1,700 IB recipients to ESA, followed by a full-scale migration of all IB recipients from February 2011. This migration will involve a re-assessment under the WCA, and it has been predicted that almost a quarter of existing IB recipients may not be found eligible for ESA.¹ DWP anticipates that all existing IB clients will have undergone the WCA by March 2014.

¹ 23% of assessments or 500,000 current IB claimants. Secretary of State for Work and Pensions, Iain Duncan Smith, before the Work and Pensions Committee, 15 September 2010. Nicholas Timmins. "Plan to shift 500,000 on to dole". Financial Times, 16 September 2010.

HIV and the WCA

Research shows that unemployment among people living with HIV may be as high as 50%;² and many people living with HIV who aren't in employment are recipients of IB.³ It is essential that the impact of the WCA on people living with HIV is understood prior to the planned large-scale benefits migration which will directly affect a large proportion of people living with HIV.

There is growing evidence that, despite the stated goal of ESA to provide the extra support people living with disabilities may need to find and stay in work, the WCA process is failing to identify many who would benefit from this help. Other disability organisations, including the Parkinson's Disease Society, Action for M.E, Macmillan Cancer Support, CAB, and the National Autistic Society have identified limitations with how the WCA assesses capability for work, which are also relevant to people living with HIV. These are discussed in detail in the next section. Moreover, analyses of the WCA to date have also uncovered a set of more generalised problems with the ESA application process, including administrative error, poor communication, and inaccurate reports.⁴ These administrative problems with the benefits system affect every claimant.

However, NAT is also aware that many people living with HIV face particular difficulties in asserting their rights in a sometimes unresponsive system. This may be due to past experiences of stigma and discrimination, the less visible nature of their disability, or because they are more likely to be affected by certain aspects of social disadvantages such as poverty and immigration status.⁵

² Over 50% unemployment in a study of people living with HIV in East London. Ibrahim, F et al (2008). "Social and economic hardship among people living with HIV in London". HIV Medicine.

³ The way that DWP publishes data means it is not possible to know exactly how many, but it remains the main disability-related benefit for people not in work.

⁴ See especially CAB. (2010). Not working: CAB assessment on the ESA work capability assessment. Published in association with Mind, March 2010.

⁵ NAT and Terrence Higgins Trust. 2010. HIV and Poverty 2010 [forthcoming].

Other disability benefits

Incapacity benefit

Until October 2008, anyone who was unable to work because of the health impacts of their HIV would have applied for incapacity benefit (IB). Assessment of eligibility for the benefit usually involved a personal capability assessment (PCA) by a healthcare professional, which may have included a medical examination.

The most recent rates of IB payments range between £68.95 and £91.40 per week. For all new claimants, IB has now been replaced by ESA.

Disability living allowance

DLA is awarded to disabled people in recognition of the extra day-to-day costs they incur because of their disability. Currently, assessing DLA entitlement does not normally involve a medical examination.

DLA rates vary between £18.95 and £121.25 per week, depending on individual

circumstances, including whether there are only care needs, mobility assistance needs, or both. DLA entitlement is not affected by whether or not someone works.

NAT's research

To achieve the fullest possible picture of the limited roll-out of ESA to date, and its impact upon people living with HIV, NAT took a mixed methods approach in our research (see appendix 2 for more detail).

ESA claimants with HIV were asked to fill out a survey following their experience through the application process, including the WCA. These surveys were given out by HIV specialist benefits advisers in their appointments with clients who were undergoing the WCA. The broader experience and knowledge of the advisers was also captured via a comments form and through semi-structured interviews.

Advisers at the following organisations volunteered to

administer the survey for NAT: Terrence Higgins Trust (Brighton and Hove); Positive East (London); George House Trust and Manchester Advice (Manchester); and Camden CAB (London). The advisers at these organisations who were interviewed and provided written evidence to our research drew upon their experiences of all the ESA cases and inquiries they have met with to date. We do not know exactly how many clients this represents in total. The aim of NAT's research was to identify potential problems with the WCA for people living with HIV, rather than make statistical claims about its impact to date. However, to give an example of one service provider's experience, Positive East reported having seen 107 individuals generating 971 client contacts (phone calls and face-to-face appointments).

Ongoing welfare reform

The changes to disability benefit started by the previous administration with the introduction of ESA and plans for the migration of IB recipients has been continued by the new government, and will feed into wider welfare reform including an upcoming review of DLA in 2013/14.

The Government announced its intention to introduce a statutory instrument which will include a range of changes to the WCA. Some of these changes, such as altering the eligibility rules around chemotherapy treatment, have been in response to criticisms already made by disability organisations. Others are based on an internal review made under the previous government. This internal review, however,

was conducted only a very short time after the ESA system had been implemented, with the express intention of altering the WCA - despite the lack of evidence about its functioning and impact to date.

In July 2010, a further, independent review into WCA commenced. Findings are not expected before December 2010, at which point the IB migration pilot will have already commenced.

About employment and support allowance

Eligibility, rules and the assessment process

Employment and support allowance (ESA) is paid at two levels: the support group and the work-related activity group (WRAG). The support group are those identified to have an illness or disability which is severe enough that they would not be expected to be able to work, or participate in work-related activities (such as job searching). Those in WRAG are not considered 'fit for work' at present, but would expect to be in the future. They are considered well enough to participate in activities which will help them move towards work.

Typical weekly payments for an individual aged over 25 are £96.85 in the support group and £91.40 in WRAG.

The assessment process of ESA is the work capability assessment (WCA), which defines eligibility for ESA based on a range of 'descriptors' of limited capability for work, categorised under 21 activities designed to assess both physical and mental health (see appendix 1 for details). Claimants score 'points' on these descriptors.

For example, some people who experience diarrhoea as a side-effect of HIV medication may wish to claim on the 'continence' descriptors:

Activity: Continence other than enuresis (bed wetting) where the claimant does not have an artificial stoma or urinary collecting device.

- Has no voluntary control over the evacuation of the bowel -15 points
 - Has no voluntary control over the voiding of the bladder - 15 points
 - At least once a month loses control of bowels so that the claimant cannot control the full evacuation of the bowel - 15 points
 - At least once a week, loses control of bladder so that the claimant cannot control the full voiding of the bladder - 15 points
 - Occasionally loses control of bowels so that the claimant cannot control the full evacuation of the bowel - 9 points
 - At least once a month loses control of bladder so that the claimant cannot control the full voiding of the bladder – 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 – 6 points
- None of the above apply – 0 points

The total points scored on all descriptors are added up. If it totals 15 or more, the claimant has passed the WCA. Successful claimants who are placed in the WRAG group are supported in moving towards work by a personal adviser.

There are an additional 11 activities with descriptors of severe limited capacity for work related activity. If a claimant is found to experience any of these descriptors, they will be put into the Support Group.

There are also some 'special circumstances' in which a claimant could qualify for ESA without passing this assessment. These 'non-functional' descriptors cover cases in which the claimant has a life-threatening disease which is currently uncontrolled, or where it would be harmful for the claimant, or any other person, if they were to enter employment. These descriptors are drawn from Regulation 29 of the ESA Regulations (discussed further below).

ESA50 Form

The first step in the WCA is the ESA Questionnaire (ESA50 form). Claimants respond to a range of questions about their disability or illness, which follow the same set of descriptors. In some cases, the DWP decision maker will find a claimant eligible based on the questionnaire alone. The claimant will also submit medical evidence from their GP or specialist about their ability to work. From the time of making the claim until the DWP decision, the claimant receives ESA payments at the 'assessment rate', which is equivalent to jobseekers allowance (£65.45 a week for a single person over 25).

Medical examination

Most claimants will then be invited to a medical assessment. It is not possible to fail the WCA without being assessed by a DWP recognised Healthcare Professional (HCP), although some may pass without the medical examination. The term 'WCA' has become synonymous with this aspect of the process. The HCP will ask the claimant questions, and possibly also undertake a physical examination, in order to allocate points against each of the descriptors. They will then send their report of the examination to the DWP decision-maker who will consider it alongside the other evidence (ESA50 and medical evidence).

The assessment process for ESA should be completed within 13 weeks.

The impact of the WCA on people living with HIV

Concerns with the design and implementation of the WCA

So far only a very small proportion of those who will eventually go through the WCA have done so – only those who have made new claims. NAT's research focussed on the experience of claimants at four organisations in three locations (Brighton, London, and Manchester). Around 20 individual cases were represented in detail in the data collected, with adviser comments reflecting their experiences in assisting between 350 and 400 clients since October 2008.

Even within this comparatively small number of cases, relative to the number which will eventually be decided once the migration from IB to ESA begins, a broad range of concerns with the WCA emerge. At this early stage, it is still clear that the WCA does not adequately assess and record the main ways that HIV can limit capacity to work.

For example, one participant in the study explained why her HIV meant that work was not an option at the moment:

"I have problems taking my medication because I have recurrent chest infections and throat infections and find it hard to swallow 7 tablets at each dose. My CD4 count is less than 200 and I experience chronic fatigue and currently have pneumonia. Additionally I have skin rashes, lesions on my eyelids and osteoarthritis following a gun shot wound sustained in Africa."

Under the WCA, she was found fit for work, and refused ESA.

NAT has two main sources of concern with the WCA as it stands. The first is its design. The points-based system, which creates a cumulative score of entitlement based on a set of fixed criteria ('descriptors' of physical and mental disability, categorised under 26 activities) is not designed to pick up some of the major barriers to employment for people living with HIV: fluctuating symptoms; fatigue; pain; sideeffects of treatment; and mental health problems.

The other cause for concern is reports about how the WCA is implemented in practice. The actions of healthcare professionals (HCPs) who make the medication examinations, DWP decision makers who make judgements, and administrative staff throughout the process reduce the likelihood that a fair and accurate report will be made of a claimant's real disability-based barriers to work.

Shared Concerns

Since the introduction of ESA in October 2008, organisations representing and supporting people living with a wide range of disabilities have expressed strong concerns about the application process for the benefit, and in particular the WCA.^a In one of the most comprehensive such reviews, Citizens Advice Bureau (CAB) found fundamental flaws in both the design and implementation of the WCA including: inappropriate selection of seriously ill clients to take the assessment; the inability of the assessment to correctly determine capacity to find and stay in work; and endemic errors in the application of the WCA by staff, resulting in inappropriate decisions.^b It is not the intention of this report to re-state all of the serious concerns already raised by other disability organisations. However, there have been some observations which are particularly relevant to the context of people living with HIV. These are referred to throughout the report.

a: Parkinson's Disease Society; Action for M.E; Macmillan Cancer Support; CAB; Mind; National Autistic Society; Disability Benefits Consortium; b: CAB. (2010). Not working: CAB assessment on the ESA work capability assessment. Published in association with Mind, March 2010.

Design of the WCA

No consideration of key HIV clinical markers

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.

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 decisionmaker who decides their claim.

Unfortunately, this does not always happen. The story of Tim (right) is one such case that made it to the appeal stage before ESA was granted. In this case, important information about his low CD4 count was submitted, but dismissed by a medical assessor who did not understand its significance. 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.

Special circumstances rules

As has been mentioned in the previous section, in addition to the main functional descriptors that make up the WCA there are additional 'non-functional descriptors' which HCPs and decision-makers may take into account. These are described in the special circumstances rules'. Specifically, regulation 35 states that:

"A claimant...is to be treated as having limited capability for work-related activity if...the claimant suffers from some specific disease or bodily or mental disablement; and...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." - Regulation 35 of ESA Regulations (excerpt - emphasis added)

This regulation can be used to show that if someone living with HIV who has a severely compromised immune system and/or is ill with an opportunistic infection went to work, they would place their own health at risk (and in the case of, for example, a TB infection, the health of other people as well).

Regulation 35 is engaged to allow entry to the support group. 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. Regulations 29 and 35 are sometimes called 'non-functional descriptors' by HCPs and decision-makers.

As these rules are exceptional, and not part of the main assessment, ESA claimants are reliant on HCPs and decision-makers to correctly interpret and apply them. The instructions in the ESA handbook to HCPs for applying regulation 35 do note that this regulation may be applicable where someone has "severely compromised immune function".

Key HIV clinical markers

There is more to the experience of living with HIV than clinical markers like CD4 count or viral load. But these are still important medical indicators.

CD4 count ➤ CD4 cells (or T-Cells) play an important role in immune function. A low CD4 count (below 200 in someone living with HIV) is an indication of low immunity and greater susceptibility to a range of illness and infections.

Viral load ➤ Describes the amount of HIV in their blood. The higher the viral load, the faster the number of CD4 cells will be reduced. Effective HIV treatment decreases the viral load.

However, as this is not stated explicitly in the regulations or on the assessment form, it is likely that this exception may 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.

Recommendations

- **Key HIV clinical indicators such as CD4 count should be recorded during the ESA assessment process. It should be clear to claimants how and when to submit this information, on the ESA50 claim form and at the medical examination.**
- **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.**

Case Study

Tim is a young man who applied for ESA with the help of his aunt and an HIV specialist benefits adviser. At the time of completing his ESA50 form, Tim's CD4 count was 19. Medical evidence from his doctor explained that at the time of diagnosis, Tim had a CD4 count of 0 and PCP, a form of pneumonia associated with a low CD4 count.

Despite providing information about his blood test results, these were not discussed at the medical examination. The HCP's record of the examination noted, contradictorily, that Tim experienced 'no side-effects' but that he experienced diarrhoea as a result of his medication. The HCP also concluded that Tim did not score any points under the incontinence descriptor.

Tim was found fit for work. His doctor submitted further medical evidence, but the case still ended up at appeal. Tim's adviser said that, "on the day, we won that appeal, without me having to say a word or even sit down... The judge looked up and said, 'oh - ESA successful, he's in the support group, that's not a problem'."

Tim is now in the support group of ESA.

Case Study

Grace had a CD4 count of 40 when she was refused ESA. She claimed JSA and attended the jobcentre for help to find work, where she was placed in a job as a cleaner. Grace became sick after only a couple of hours of work, owing to her compromised immune system. She was ill for a fortnight.

Her HIV-specialist benefits adviser said, "me and the social worker went ballistic at her when we found out [that Grace had gone to work] but she said 'I wanted to try because I don't want to claim'. We said 'we know darling but you're too knackered so don't.'"

The adviser took Grace's case to appeal, and was successful. Grace is now in the support group.

Fluctuating symptoms and general fatigue

The WCA points system is also limited when it comes to properly accounting for fluctuating conditions, including HIV, and the impact this variability has on ability to find and stay in employment. 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”.⁶ 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 for 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 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”.⁷ 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 longstanding. 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 their main barriers to work were side effects of treatment, fatigue, and managing pain, said that when she tried to give a 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 (the range of 50-75%) that would be accrued if the claimant experienced limited capability the majority of the time. 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

► **The WCA should take into account the impact of fluctuating conditions, such as HIV, on ability to enter and remain in employment. 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’.**

⁶ DWP. (2008). ‘A guide to Employment and Support Allowance- The Work Capability Assessment’. ESA214.

⁷ Atos Medical Services (2009). ‘ESA Handbook’. Version 4.

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.⁸ 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 common side effects noted above, diarrhoea is the only one to be represented in the points-system. However, to pass the WCA on these grounds alone, the claimant would have to be able to show that they:

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 an claimant in this situation, especially if they were in an inappropriate role, less supportive workplace, or if it was a common occurrence.

"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

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. 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 antiretrovirals. 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'.

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

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.⁹ 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.¹⁰

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 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

- 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

- 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
- 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
- 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
- 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.¹¹ 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.

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

The interaction of multiple conditions

When introducing the WCA, DWP expressed concern that the previous assessment for incapacity benefit had allowed for some “double-counting”, where multiple descriptors appeared to measure the same activity (in particular some around mental health).¹² But the points system introduced in response 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 the conditions. The impact in limiting their chances of entering employment is more than the simple sum total of points would suggest.

Recommendation

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

¹² “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>

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.¹³ The WCA was intended as an alternative to a prevailing 'sick note culture', but still centres on the need for claimants to effectively provide a standard 'sick note', even those with long-term conditions.¹⁴

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.

In relation to HIV the social model of disability would, for example, take into account the impact of HIV-related stigma on mental well-being and self-esteem and the often exacerbating interaction between these issues and physical impairment. An approach that focuses on the social dimensions of disability would also consider the difficulty and reluctance many experience in disclosing their HIV status to potential or current employers and the impact this has, for example, on ability to access reasonable adjustments. When HIV as a disability is

considered in this way, it is clear that to get back into work individuals need specialised and extended support around managing their condition and its disclosure in the workplace.

The personalised support provided by ESA in the work related activity group (WRAG) is well-positioned to address these 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. It is important that the WCA process can take account of such social dimensions to an individual's disability and offer appropriately the time-limited support of WRAG.

There will of course be potential claimants with HIV who are in good physical and mental health and are therefore not eligible for either ESA group. 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. NAT is concerned that the current benefits system does not show sufficient awareness of the social dimensions of HIV, and disability more broadly, to meet these needs.

Recommendations

- **The WCA process should be amended to capture appropriately the wider social aspects of disability which act as barriers to employment, with referral to the WRAG group for those who would benefit from support in dealing with the combination of moderate impairments and significant social barriers to employment.**
- **Specialised support should be available for all JSA claimants who have a disability, as well as staff training in the social dimensions of disabilities including HIV, and specialised support for those with stigmatised conditions.**

¹³ ME Association (2009). 'Bending the rules- feature on the Work Capability Assessment'.

¹⁴ National Autistic Society (2009). 'Don't write me off- Make the system fair for people with autism'.

Implementation of the WCA

When ESA was introduced, the Department of Work and Pensions estimated that half of those undertaking the WCA would be found eligible for the benefit, and the other half fit for work.¹⁵ However, statistics show the number of rejected claims to be much higher. Of claims resolved prior to May 2010, 66% were found ‘fit for work.’¹⁶

ESA50 form

No one involved in NAT’s study reported spending less than an hour filling out the ESA50 form, a self-administered questionnaire which is the first step in providing evidence towards an ESA claim. One participant noted that he spend four and a half 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 reported 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.¹⁷

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, as noted earlier, 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.”¹⁸

Participants in NAT’s study indicated that this guidance is not always followed. The important information about their HIV that survey respondents said they did not have

the opportunity to discuss in their medical assessment included:

- side effects of treatment
- day to day changes in my health
- depression/anxiety
- fatigue/tiredness
- managing pain

This is consistent with the growing evidence base collected by other disability organisations, in which there are plenty of examples of HCPs not only refusing to hear the additional information relevant to claimant’s case, but in being brusque, intimidating or simply rude in doing so.¹⁹ Claimants report the HCP simply holding their hand up to stop them from talking.²⁰ 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.”

¹⁵ NAT. Decision making and appeals in the benefits system: response from NAT. September 2009.

¹⁶ 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

¹⁷ Parkinson’s Disease Society; Action for M.E; Macmillan Cancer Support; CAB; Disability Benefits Consortium; National Autistic Society

¹⁸ DWP. (2008). p13

¹⁹ 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.

²⁰ Parkinson’s Disease Society. (2009). “Of little benefit and not working: People with Parkinson’s experience of Employment and Support Allowance”. October 2009.

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 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 make them 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.

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 found eligible for ESA, and being left without the support they need or are entitled to. Instead, 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.

Recommendations

- 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.
- 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.

Recommendations

- 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.
- 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.

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".²¹

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.²²

NAT's research has found that at present, the interpretation of medical evidence in light of the ESA claim is extremely narrow. Evidence from doctors is discounted because it does 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.

In great part then, this is an issue of administration. 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. This would lead to more accurate decisions and 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.

Recommendations

► **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.**

► **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.**

²¹ DWP. (2008). p15

²² See CAB (2010); Parkinson's Disease Society (2009)

Case Study

An HIV-specialist benefits adviser took a case 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]?" The claimant's HIV-specialist benefits adviser tried to explain the serious health consequences of interrupting treatment, but 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.

The work-related activity group

As well as revealing the unexpectedly high proportion of ESA claimants who are being found 'fit for work', the official statistics around ESA indicate a possible underuse 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.²³ 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 support 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 survey respondent 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 WCA points system needs to be reviewed so that claimants who show any capability for work are not found 'fit for work' – many of these claimants should be placed in the Work Related Activity Group with a programme of support to help them move into work.**

²³ "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 Work Related Activity Group

As with other work-focused benefits like jobseekers allowance (JSA), the WRAG component of ESA requires the claimant to undertake a range of prescribed activities to receive the benefit. For WRAG, this means attending a series of 'work-focused interviews' with a specialist adviser.

Unlike JSA, though, WRAG can offer a disability-focused programme of support including:

- training or re-training courses
- condition management programmes
- liaising with employers about reasonable adjustments

And importantly, benefits under WRAG are not ceased if the claimant does not find work.

example. His claim was delayed so much that when his case was finally resolved he received over £700 in arrears. In the meantime, he had to rely on friends and family, and a grant 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 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.

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 generalist 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 a complex process 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. The case of James is a particularly extreme

Recommendation

■ **As recommended by the House of Commons Work and Pensions Committee, the Secretary of State should report on DWP decisionmaking standards annually. These reports should be used as a basis for improving decision-making within DWP.**

Appeal and review

Since its introduction in October 2008, ESA has become the most-appealed benefit, with a 40% success rate.²⁴ 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 non-functional descriptor (regulation 29) or deferred the WCA for medical reasons (such as hospitalisation). In only 0.3% of cases the claimant was awarded the WRAG rate of ESA because a DWP decisionmaker decided against the recommendation of the HCP.²⁵

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

²⁴ 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; BBC. 2010. "New benefits system labelled unfit". 25 March. <http://www.bbc.co.uk/news/10159717>

²⁵ 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

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, seeking advice appears to be the exception rather than the rule.

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 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.

Recommendations

► 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.

► 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 to 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 and other requirements to prove eligibility for disability-based benefits in many cases only add 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 characterized by delays and a culture of disbelief, can make it even harder. There can be serious consequences of poor 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.²⁶

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.²⁷ Positive East, who participated in NAT’s research, report that ESA has generated in the region of 670 face-to-face appointments with their benefits advisers, at an average length of 45 minutes to an hour.

Recommendations

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

²⁶ CAB (2010); Macmillan Cancer Support. (2009). “Failed by the system”.

²⁷ CAB (2009).

Case Study

Following domestic violence Shaun, who is HIV positive, left his partner's home and became homeless. He was housed temporarily in a hostel by his Local Authority, and applied for ESA, housing benefit, and council tax credits.

He experienced a range of administrative problems with his ESA claim, which was eventually lost. His benefits adviser tried unsuccessfully to retrace the claim, but it was never found. He made another claim. This time a decision was made that as an EU National, he did not have the 'right to reside', despite being in the UK for some time. He appealed, but the appeal request was also lost and untraceable.

During the application process, Shaun had requested and received a crisis loan to tide him over. After his ESA claim was lost he made a second crisis loan application, but this was also refused on the basis that he did not have the right to reside. Shaun's adviser appealed this decision. At the hearing, the Social Fund Inspector found in favour of Shaun, and judged that the DWP assessment on his right to

reside was inaccurate.

However, in the meantime Shaun's local authority had suspended his housing benefit and council tax benefit on the basis of the same DWP assessment of his right to reside. He was also inappropriately asked to pay service charges towards his housing from the small payments of crisis loan that he had received, or he would be evicted. The local authority also told Shaun that he was not eligible for housing because of DWP's judgement.

The pressure on Shaun's physical and mental health during this time was considerable. On a number of occasions he contacted his support organisation threatening to end his life.

In a further appeal to DWP Shaun's adviser highlighted the hardship that the inaccurate decision was causing and the detrimental effect to his other rights, including housing, as well as the contradictory decision of the Social Fund Inspector on the question of right to reside. The appeal was successful.

Recommendations

NAT's study of the impact of ESA to date shows that the barriers to work experienced by people living with HIV are not fully reflected by the WCA, either in design or implementation. The research has also highlighted serious gaps in the HIV awareness and knowledge of those responsible for implementing the WCA, both DWP staff and Atos healthcare professionals. More broadly, errors in administration, communication and decision-making processes are adversely affecting ESA claimants living with HIV. Despite these problems, DWP is continuing on with plans to migrate thousands of existing benefits recipients into the new system.

The design of the WCA

- a.** Key HIV clinical indicators such as CD4 count should be recorded during the ESA assessment process. It should be clear to claimants how and when to submit this information, on the ESA50 claim form and at the medical examination.
- b.** 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.
- c.** The WCA should take into account the impact of fluctuating conditions, such as HIV, on ability to enter and remain in employment. 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'.
- d.** The WCA points system needs to be reviewed so that claimants who show any capability for work are not found 'fit for work' – many of these claimants should be placed in the Work Related Activity Group with a programme of support to help them move into work.
- e.** 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.
- f.** The points system should be changed so that anyone who scores points on two separate descriptors would pass the WCA.

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.** 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.
- i.** 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.
- j.** 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.

HIV awareness among DWP staff and Atos contractors

- k.** 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.
- l.** 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, communication and decision-making standards

m. 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 decisionmaking within DWP.

n. 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.

o. 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.

p. 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.

The WCA and welfare reform

q. The WCA process should be amended to capture appropriately the wider social aspects of disability which act as barriers to employment, with referral to WRAG for those who would benefit from support in dealing with the combination of moderate impairments and significant social barriers to employment.

r. Specialised support should be available for all JSA claimants who have a disability, as well as 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 (Harrington) 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.

Appendix 1: descriptor categories

Test for Limited Capability Work - eligibility for WRAG

The physical functions

The physical functions in the limited capability for work test are grouped into 11 different types of activity. These are:

1. Walking
2. Standing and sitting
3. Bending or kneeling
4. Reaching
5. Picking up and moving things
6. Manual dexterity
7. Speech
8. Hearing
9. Vision
10. Continence
11. Remaining conscious

The mental, cognitive and intellectual functions

These functions in the limited capability for work test are grouped into sets of activities under the following 10 headings:

1. Learning or comprehension in the completion of tasks
2. Awareness of hazard
3. Memory and concentration
4. Execution of tasks
5. Initiating and sustaining personal action
6. Coping with change.
7. Getting about
8. Coping with social situations
9. Propriety of behaviour with other people
10. Dealing with other people

Additional test for limited capability work - eligibility for support group

1. Walking.
2. Rising from sitting.
3. Picking up and moving things.
4. Reaching.
5. Manual dexterity.
6. Continence.
7. Maintaining personal hygiene.
8. Eating and drinking.
9. Learning or comprehension in the completion of tasks.
10. Personal action.
11. Communication.

Appendix 2: about the review

More detailed information about how NAT conducted our research

Approach

NAT chose a mixed-methods approach of surveys of ESA claimants and interviews with HIV-specialist benefits advisers, to get the most complete mix of individual experiences, personal case studies and professional expertise possible.

The following organisations volunteered to administer surveys and provide additional comments from benefits advisers: Camden CAB (London), George House Trust and Manchester Advice (Manchester), Positive East (London), and Terrence Higgins Trust (Brighton & Hove)

Selecting participants

Participants for the study were selected with the help of organisations providing benefits advice services for people living with HIV, in a range of locations.

Advisers at these organisations were asked to invite their clients to participate if they

were at any stage of the ESA application process in the time frame covered by the study.

NAT acknowledges that this method of selecting participants creates a bias towards those who had sought help from a welfare adviser in order to make their application, and does not include those who did not seek advice because they did not have problems with the process. However, while this may not be representative of the population of people with HIV who apply for ESA as a whole, it has the advantage of highlighting the areas of difficulty which have been experienced in the application process. It should also be kept in mind that not everyone who applies without assistance finds the process unproblematic. The extremely high demand for welfare and benefits advice services was evident at all the organisations which were involved in the study.

Time frame

The four partner organisations administered the questionnaire between 1 March and 14 June 2010. The DWP sets out a typical timeline for the ESA application process, which indicates that all the participants' applications should be finalised within 13 weeks. For this reason, it was anticipated that a research time-frame of 15 weeks should capture some complete experiences of the process from start to finish, as well as insights from specific stages of the process.

The survey

The questionnaire, adviser comment sheet (discussed below), background to the study and instructions for advisers were sent to the four organisations via email to print and administer in pre-existing appointments with clients during the time-frame of the study.

As described previously, the ESA application process takes up to 13 weeks (see 'model timeframe' in the Introduction). In order to collect as much relevant information about participants' experiences as possible, and as soon as possible, the survey was presented in four parts:

Part 1: Making the application

Filled out after the application has been lodged.

Part 2: ESA questionnaire

Filled out after the ESA50 questionnaire has been received by DWP, and the invitation to medical examination has been made (or a decision has been made without examination).

Part 3: The Work Capability Assessment

Filled out after the medical examination appointment, which will also include a work-focused health-related assessment interview.

Part 4: The ESA decision

To be filled out after the client has been notified of a decision around their claim

Splitting the survey into sections also made it easier to include the responses of participants who had only experienced part of the process. For all participants, the four-part format meant there were less questions to answer at any given time, which made the study less onerous for them and their advisers.

The survey included a mixture of multiple choice and open-ended questions, with spaces for extra comment on each issue covered. Feedback was sought from all advisers on the format, content and wording of the questionnaire prior to finalising the survey.

The participants filled out the survey independently, but with the option of asking their adviser to clarify any of the questions which weren't clear. Where this wasn't possible, advisers encouraged their clients to take parts of the survey home to fill in.

Ethics and confidentiality

Advisers were instructed to tell participants that the survey was entirely voluntary. There was no pressure upon clients to be involved. However, to encourage participation, advisers explained that:

- Individual experiences are the best evidence of how the application process works in practice, and how it affects claimants.
- The survey was an opportunity for clients to make decision-makers aware of any problems they have had with applying for ESA.
- Other support organisations who have surveyed their clients about the ESA application process have already published reviews of the system, which been heard by government. NAT wants people living with HIV to have their voice heard as well.

Confidentiality of participants was also guaranteed, with systems in place to collect responses anonymously. Advisers used codes to keep each client's responses together, but still anonymous.

Adviser comment sheet

Advisers at the four organisations were also asked to comment on their experiences of the ESA application process.

The adviser comment sheet invited them to make comments about:

- the ESA50 form
- the Work Capability Assessment
- the Work-focused Health-Related interview
- why your clients need to apply for ESA
- what proportion of your clients who apply are found eligible for ESA
- reconsideration and appeal mechanisms, how often you use them, and what

the outcomes have been

- issues around medical evidence, including sick notes and reports from consultants and GPs
- ...anything else they thought would add to the study

NAT kept in regularly contact with advisers throughout the data collection process to support them in administering the survey.

Interviews with advisers

NAT also conducted interviews with benefits advisers who had participated in the research, to gain a more in-depth understanding of the impact of the WCA to date. All the advisers who participated in the research were expert in both the benefits system and HIV. The interviews were semi-structured, and covered the same issues as the survey. Advisers were particularly encouraged to provide examples and case studies of the main concerns with the WCA.

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