Not working
CAB evidence on the ESA work capability assessment

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Executive summary

Employment and support allowance (ESA) was introduced in October 2008 to replace the existing incapacity benefit (IB) for new claimants. It aims to give more help to those who might, with support, be able to work.

Citizens Advice has been monitoring the impact of the new benefit, and this is our second report since its introduction. Limited capability, published in November 2009, covered the administration of the benefit, and this report looks at the assessment process. Bureaux advisers have expressed grave concern at the number of people unexpectedly being found fit for work. This report therefore examines three key aspects of the ESA assessment process: who is being selected for the work capability assessment (WCA); its design and content; and how it is carried out in practice.

The main findings concern problems with each of these aspects of ESA assessment:

- **Seriously ill people are inappropriately subjected to the WCA.** Under IB if someone was seriously ill, information was sought from their own doctor and if the diagnosis was confirmed, they were exempted from the assessment. There are fewer exemptions for ESA, which means that people with debilitating conditions or serious disabilities are being subject to the WCA, and some are found ineligible for the benefit. Others in difficult but short-term situations are being found ineligible, just when they are most in need of the support of ESA.

- **The assessment does not effectively measure fitness for work.** It does not take sufficient account of variable symptoms. There is little recognition of generalised pain and exhaustion, or the seriousness of an underlying condition. It takes no account of the context of the work environment, including a person’s education, skills and circumstances, or the discrimination they may face in looking for work, all of which can significantly affect the scale of the person’s barriers to work. The guidance for the health care professionals (HCPs) administering the test gives extreme examples, which is likely to lead to very harsh decisions.

- **Application of the assessment is producing inappropriate outcomes.**
  
  Citizens Advice and other organisations have been concerned for many years about the quality of medical assessments for benefits. We still hear repeated reports of rushed assessments, assumptions being made without exploration, inaccurate recording and poor recognition of mental health problems.

  These problems create major difficulties for our clients and undermine the Government’s aims for ESA. People with serious illnesses and disabilities who could not reasonably be expected to work are being found fit for work. Other people who might, with considerable support, be helped into work, are effectively being ‘written off’ by being found fit for work and therefore ineligible for ESA. Many of these people are too ill to sign on, or are not eligible for any other benefit, and so are left with reduced incomes and no help or support to find work. Furthermore, many of those found ineligible for ESA also lose access to an extremely helpful route into sustainable work through the disability element of tax credits.

Research shows that claimants who move off benefits and (re-)enter work generally experience improvements in income, socio-economic status, mental and general health, and well-being. However it also shows that “those who move off benefits but do not enter work are more likely to report a deterioration in health and well-being”.1

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1 Waddell and Burton (2006) Is work good for your health and wellbeing?
Recommendations

There should be a full and independent review of the work capability assessment (WCA) which looks at not just the individual descriptors but at the underlying questions of who should be eligible for the benefit, the validity of the test at identifying those people and the accuracy of the medical assessments.

Exemptions and process

- The range of exemptions from the WCA should be extended. Decision makers should have the power to allocate claimants to the support group or the work-related activity group, based on the written evidence, so that these claimants are not subject to the WCA.

- Decision-makers should be given the discretion to take account of exceptional circumstances which indicate that the claimant is likely to return to work, but is not immediately ready to do so. They should have the power to make a decision for a short period on the basis of written evidence from the claimant’s own doctor.

- The process for obtaining evidence from the claimant’s doctor through the IB113 and the ESA113 should be reinstated to the previous level of frequency, and IB50s and ESA50s should not be sent automatically before considering whether one is needed.

The design of the WCA

- The assessment should have two stages. Capacity for work should be tested initially by functional ability, and if the impairment reaches the prescribed level – as in the current WCA – the claimant should be automatically awarded benefit.

  However if functional capacity is higher than the prescribed level, so the person does not automatically qualify for benefit, there should be a further, ‘real-world’ test, based on the social model of disability.

- The guidance and training for the HCPs should be urgently reviewed.

- Help and support should be personalised and offered on the basis of need. There is an urgent need for recognition that – contrary to the Government’s intentions – some people are being ‘written off’ by being found capable of work, and therefore being removed both from benefit support and from the help and support they need to find work.

Research

- A health impact assessment should be conducted as soon as possible. As well as comparing ESA with IB, it should also look at what would be the health implications of allowing more sick and disabled people to remain on ESA while being given the help and support to look for work.

- At present the descriptors are based on expert opinion. Research is necessary into the actual, real-world, effect of different disabilities or illnesses on different types of employment. This research should also include what is happening to those being found ineligible for ESA.

- As a matter of urgency the reliability of the WCA tests should be independently measured, using the standard measures of the accuracy of any diagnostic or classificatory test (its false positive and false negative rates).

- The results of the WCA report should be routinely sent to claimants, who should be given opportunity and time to correct inaccuracies, in order to prevent further problems – and costs – later in the claiming process.
OR, at the very least, DWP should conduct regular surveys to validate the factual accuracy of WCA reports.

Migration of those on incapacity benefit

In view of the problems identified in this report, those being migrated from IB, who will have been away from the labour market for a long period, should be guaranteed a substantial period on the more active benefit, to allow time for them to adjust to new circumstances. They could be subject to the conditionality as appropriate and receive all the help and support offered by ESA before they are subject to the WCA. This would also allow time for the review of the WCA.

Introduction

The Citizens Advice service is a network of 416 independent advice centres in England and Wales providing free, confidential and impartial advice and advocacy from over 3,300 outlets, in high streets, community centres, health settings, courts and prisons. Over 6,000 paid staff and 21,000 trained volunteers deliver advice to help clients deal with six million new problems a year, of which benefits and debt make up about 65 per cent of all queries.

From 27 October 2008 employment and support allowance (ESA) replaced incapacity benefits (IB) for new claimants who can not work because they are sick or disabled. The test used to assess whether someone is eligible for ESA is called the work capability assessment (WCA).

ESA forms a central element of the Government’s policy to help people move from incapacity benefits into work. “At the heart of these reforms is a determination to change the attitude that people on incapacity benefits are effectively written off. Instead of the concept of incapacity for work, ESA entitlement will be based on limited capability for work”2. Citizens Advice supports the principle of helping more people into work, but we are concerned that the way the assessment for ESA is being implemented is working against this principle.

In the first three quarters of 2008/09 bureaux saw 59,012 clients who had an enquiry about incapacity benefit and a further 5,834 about an ESA claim (ESA was introduced in the third quarter of 2008/09). This makes a total of 64,846 clients who wanted advice about a sickness benefit. In the first three quarters of 2009/10 bureaux saw 31,164 clients with a query about their incapacity benefit and 60,569 clients with a query about ESA, making a total of 91,733 clients seeking advice about a sickness benefit. This is an increase of over 40 per cent in the numbers wanting help with sickness benefits since the introduction of ESA.

In the last quarter alone (October to December 2009), we saw 22,618 clients wanting advice about ESA. Over a very similar time period (September to November 2009) a total of 102,500 people had their claim for ESA assessed by DWP. The numbers of people coming to bureaux for help and advice about their ESA claim is obviously a sizable proportion of those being assessed (just over 20 per cent) and not just a tiny minority of problem claims.

We therefore believe we are in a strong position to judge whether there is a systemic problem rather than a few perverse cases. Any new benefit is bound to cause some problems as it is introduced, but anecdotal evidence among bureaux staff and welfare rights advisers suggests that the operation of ESA is causing as much concern as the introduction of tax credits in 2003, and our qualitative data base saw almost 4,000 cases submitted on ESA from March 2009 to March 2010 – approximately nine per cent of the annual total across all our issues. To gain further insight into these problems, we ran two workshops in Yorkshire and London for advisers and welfare rights workers dealing with clients claiming ESA. Many of the

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2 Statement by Lord Mackenzie of Luton, Parliamentary Under-Secretary, DWP (22 May 2008), Hansard, House of Lords, c 1,645
advisers brought anonymised details of cases, including reports from the WCA and the letters of evidence supplied by the clients’ GPs or consultants. In addition to this supplementary case studies were provided by Mind.

Our evidence suggests that seriously sick and disabled people are being found ineligible for the benefit, and it is currently not clear what happens to many of these people – although Government expects to publish some research in summer 2010. The Government’s own figures also show that the number of people being found eligible for the benefit under the assessment process as currently operating is 20 per cent fewer than expected. Research shows that claimants who move off benefits and (re-)enter work generally experience improvements in income, socio-economic status, mental and general health, and well-being. However it also shows that “those who move off benefits but do not enter work are more likely to report a deterioration in health and well-being”.

We have heard disturbing reports of deteriorating health and serious financial difficulty for clients, as a result of inappropriate ESA decisions.

The Government’s intention is to migrate all 2.4 million current IB claimants onto ESA by March 2014. Of this group approximately half (almost 1.2 million) are receiving contribution-based benefits with no means tested benefit top-up. No one who is migrated from IB is likely to be eligible for JSA (contribution-based) if they are found fit for work, because of the need to have been in paid work in the recent past. The majority of the group who are not eligible for a top-up on their current sickness benefit, are also unlikely to qualify for JSA (income-related). This means that a large proportion of those found ineligible for ESA but who are unable to work, will have no benefit to replace the income they have lost as a result of their illness or disability.

Many of these people will have been living on sickness benefits for several years, and even if they are legitimately found fit for work, they will still need time to adjust to new expectations and new patterns of behaviour. We are concerned that further hardship and distress will be caused for people with serious illnesses and disabilities, unless the assessment process is refined and improved before the migration begins, and robust support mechanisms are in place.

We believe that long-term IB claimants newly found fit for work should be allowed time on ESA before being moved to JSA.

This report analyses from our evidence where the system appears to be going wrong, details the resulting distress and hardship experienced by CAB clients, and makes recommendations for improvements.

The claiming and assessment process

When claimants first apply for ESA, anyone with a terminal illness should automatically be granted the benefit. The majority then enter a 13-week assessment phase and start on the same benefit rate as JSA. By the end of this phase, claimants should have undergone the work capability assessment (WCA). The assessment determines whether they are considered to have sufficient limitation on their ability to work to be eligible for ESA, and, if so, whether they are allocated to the work-related activity group or are so seriously limited in their ability to work that they are allocated to the support group. Clients in the support group may look for work, but have no obligation to do so, whilst those in the work-related activity group are expected to attend work-focused interviews, and be supported by a programme of personalised help – take steps to prepare themselves for work.

Once a claimant has been allocated to the work-related activity group, s/he will attend a work-focused health related assessment
(WFHRA) to assess the support needs required to help the claimant move into work. This was previously conducted at the same time as the WCA, but frequently generated inconsistent results. Claimants could be found fit for work by the WCA, but not immediately work-ready by the WFHRA:

A client from a Leicestershire bureau was made redundant and four weeks later his wife died. He became very depressed. His GP felt it was going to take some time before he could focus on looking for work and signed a sick note for four months. He went for a WCA four weeks after his wife died, was given no points and his ESA stopped, even though the WFHRA recommendation was that he would be ready for work in six months. The bureau reported that the client’s stress and depression were made worse by the ongoing problem and the appeal process.

The WFHRA is the only part of the test that even begins to assess the context of a client’s journey to work, and yet it is only applied after and if the client has been judged eligible for the benefit on the basis of the functionality test. We recommend that the assessment for eligibility includes a contextual, real-world element as well as the functionality test.

Statistics

DWP figures have been fairly consistent since ESA was first introduced: the latest ESA WCA statistical release in January 2010 shows that, of total claims, 38 per cent have their claim closed before a decision is reached, and for seven per cent the assessment is still ongoing. Five per cent are allocated to the support group and 12 per cent to the work-related activity group, while 38 per cent are found fit for work. Of those who have been assessed, nine per cent were allocated to the support group.
The introduction to ESA on Directgov states that “Employment and support allowance offers you personalised support and financial help, so that you can do appropriate work, if you are able to.” And “If you have an illness or disability that severely affects your ability to work, you will get increased financial support and will not be expected to prepare for a return to work.” In the structure of ESA, these two situations translate into the work-related activity group and the support group mentioned above.

According to the ESA regulations the WCA sets out to establish “whether a claimant’s capability for work is limited by the claimant’s physical or mental condition and, if it is, whether the limitation is such that it is not reasonable to require the claimant to work.”

**Hurdle one – Are the right people being selected to test?**

We have identified three key factors which contribute to some of the unexpected outcomes in the assessment process – firstly that certain exemptions applicable to IB are not included in ESA; secondly, that changes have occurred in the process for collecting information; and thirdly, the assessment is not flexible enough to respond to short-term special circumstances.

**Exemptions**

In assessing whether someone is entitled to IB, there are a number of situations in which they are “deemed as incapable of work”, including situations such as receiving radiotherapy treatment or having given birth in the last two weeks. There is a further group of situations where claimants are exempt from assessment and so do not have to undergo a personal capability assessment (PCA). They are automatically found to be incapable of work.

Assessment for ESA also includes “special circumstances” in which claimants can automatically be considered as having limited...
capability, and therefore eligible for the benefit. These “special circumstances” cover far fewer situations than for IB. Amongst others, the following exemptions from the PCA are not included in the “special circumstances” for ESA:

- Receiving the higher rate of disability living allowance (DLA) care.
- Registered blind.

Medical evidence to show:

- A severe and progressive neurological or muscle wasting disease.
- A severe and progressive form of inflammatory polyarthritis.
- Progressive impairment of cardio respiratory function which severely and persistently limits effort tolerance.
- A severe and progressive immune deficiency state characterised by the occurrence of severe constitutional disease, opportunistic infections or tumour formation.
- A severe mental illness which severely and adversely affects mood or behaviour and which severely restricts social functioning or awareness of the immediate environment.

It is clear that objective testing must be used to identify those eligible for a state benefit, but bureaux are seeing some very puzzling outcomes, in which clients with serious problems are being found ineligible for ESA, when they have clearly debilitating conditions – for example, a woman who needed oxygen for 16 hours a day was found fit for work. This would have been reason for exemption under IB rules.

A northern bureau saw a client in his fifties, who had worked in skilled manual work all his life. He was self-employed when he developed rheumatoid arthritis and heart problems. He continued working for as long as he could, but it was affecting his wrists, elbows, knees and hips so he was unable to do any of his normal work. He applied for ESA but at his WCA he was just awarded six points and thus found capable of work. His consultant commented that “he continues with an active inflammatory arthritis which has been causing progressive problems. …upper limb problems and also mobility affected. …Until his arthritis comes under control he will have significant problems which are likely to impact on his ability to work and also activities of daily living.” At tribunal, he was found incapable of work and placed into the support group.

A bureau in the Midlands saw a client who had a genetic kidney disorder and who had had one kidney and part of the other kidney removed. She also had sciatica and spondylosis. She was found not to have limited capability for work. She has since been told that her condition may be terminal.

People diagnosed with recognised serious illnesses are being found fit for work in a way which did not happen under IB rules:

A Yorkshire bureau saw a woman in her forties who was working full-time and was enthusiastically looking forward to starting a new job, when she became ill. At first it was thought she had a viral illness, but she was subsequently diagnosed with lupus erythematosus and transverse myelitis. She was in a great deal of pain in her muscles and joints and had extreme fatigue. At times her balance was affected and she could not walk without someone to support her. Sometimes she lost sensation in her legs, and on her worst days she could not walk at all. Any exertion such as walking 40 or 50 metres led to days in bed. She had had a bad reaction to some of the treatment and an ECG showed her heart muscle had been damaged. Her husband had to come home from work each lunchtime to help her. Her immune system was weakened, so she had to
be careful when mixing with others. She claimed ESA but was given six points in the WCA and found capable of work. Her doctor supported her claim and she is currently appealing, but under IB she would probably have been exempt and would have avoided this process.

We have seen several examples of clients who have struggled to keep working after a diagnosis of Parkinson’s disease. They finally give up work when the symptoms have become too bad for them to continue, only to be found ineligible for ESA. Again, they would probably have been exempt under IB rules:

A Wiltshire bureau reported that a client with Parkinson’s disease had both physical and cognitive/intellectual difficulties. He went for a WCA for ESA and was awarded no points despite the following problems: difficulty in standing longer than 10 minutes and tendency to fall; difficulty in open spaces in the dark or dull light, which led to his panicking and falling; inability to negotiate steps safely; panic in a crowded room if he had to get from A to B without support; deteriorating speech – he slurred his words and could not control saliva; very poor short term memory, with inability to recall conversations that happened a few hours previously; difficulty with concentration and inability to do anything in a systematic or ordered way. His mental health had suffered because of his difficulties. He had been awarded DLA.

The process for collecting the information

When someone first claims IB or ESA they must provide a medical certificate from their GP. Before October 2008 for IB, if the medical certificate indicated that the person was likely to be exempt from the PCA, a form (IB113) would be sent by DWP to their doctor to collect further information. If the doctor confirmed that the patient fell within one of the exempt groups, the claimant would be awarded the benefit. Now, however, when someone claims IB or ESA, a computer is triggered to send the client an IB50 or an ESA50 which must be completed with information about their condition and their ability to function. The only exception is if the claimant has said they are terminally ill. A form (ESA113) may subsequently be sent to the claimant’s doctor if the HCP believes there is evidence they should be in the support group. We understand from doctors and community mental health teams, however, that forms are sent to the clients’ own doctors much less frequently than they were before October 2008.

An adviser with a community mental health team saw a woman who had been an in-patient for about two years, had been discharged into supported housing and had had her benefit stopped. She had failed to show any of her support workers the IB50 form or two letters calling her to attend a PCA, so it only came to their attention when the benefit stopped. They pointed out that failure to bring the correspondence to their attention was due to her severe mental illness, and an IB113 would have avoided a lot of distress for this woman.

We recommend that the process for gathering information for the assessment which existed before October 2008 be reinstated so that ESA113s are used more frequently and greater weight can be given to the evidence of the claimant’s own doctor or consultant in situations where someone has a serious illness.
Impact on people with severe mental health problems

Benefit advisers have been added to community mental health teams precisely because financial stability is essential to mental health. They report that this change in procedure since October 2008 has led to particular problems for those with serious mental health problems. Advisers say that before October 2008 they would rarely have to help claimants complete IB50 forms, since people being seen by a community mental health team have – by definition – serious mental health problems and were usually considered eligible for the benefit without having to undergo the functional assessment. The consultant psychiatrists, community psychiatric nurses and advisers on these teams have expressed their concern about the numbers of clients being called for assessment, and then being refused ESA, as the stress of the appeal process over a period of months can further damage clients’ mental health.

An adviser with a community mental health team recorded grave concerns about a client diagnosed with bipolar disorder but who had no insight into his condition. He had a WCA and was found fit for work. The client signed on, and was delighted because he believed this showed he was right all along and he was not ill. The psychiatrist wanted this decision to be challenged but it was not possible because the client did not want to appeal. The psychiatrist believed him to be seriously ill and was very concerned about the damaging effect of this decision on his future health, as it made it even more difficult to get him to accept the help he needed.

An adviser from a community mental health team reported that almost all their new clients applying for ESA are being refused benefit. In the last few months, she has helped 10 clients appeal ESA decisions: three have been resolved, and the other seven are all waiting to go to tribunal. None of these clients would be getting the very significant resources of the community mental health team if they were not seriously mentally ill. Under the IB rules, this would be used as an indicator that there was a severe mental health problem and the benefit would be awarded. The stress and worry of the ESA process is damaging the clients’ mental health and delaying recovery and the possibility of an eventual return to work.

Another adviser with a community mental health team echoed these concerns and pointed out that clients with severe mental illness frequently lack insight into their condition, so if they complete an ESA50 themselves, it does not give a good indication of their functional capability.

She described a client with a diagnosis of paranoid schizophrenia who lacked insight into his mental health and was non-compliant with treatment. He had paranoid thoughts, had hallucinations and heard voices, and had suicidal thoughts, having previously attempted suicide. He claimed DLA and was awarded higher rate care and lower rate mobility. He was detained under Section 3 of the Mental Health Act 1983 (MHA83). Regulations state that a claimant should be treated as having limited capability for work on any day that they are receiving hospital treatment – thus he should have been automatically placed in the support group. He received the ESA50 in hospital and returned it while he will still detained. The ESA50 was not completed accurately as he was acutely unwell, but he attended a WCA a few months later and was found fit for work.

Another client seen by a specialist mental health worker had been diagnosed with bipolar disorder,
paranoia, delusions, mood swings, low self-esteem and grandiose ideas. She was entitled to DLA higher rate care and lower rate mobility. She was admitted under Section 3 of the Mental Health Act 1983, due to being a danger to herself and others. A month after leaving hospital she completed an ESA50 and a month after that she attended a WCA: she scored no points and was found fit for work. The decision has been reconsidered but not revised and this is awaiting an appeal date.

The NHS invests considerable amounts of public money and resources in treating and supporting the patients of community mental health teams, on the basis that they have been diagnosed as seriously ill. These care teams are experts at assessing mental health and their expertise and knowledge should be sought, rather than decisions being made on the basis of an assessment by a generalist HCP, who – compared with a consultant psychiatrist – will have limited experience of mental health. Far more weight should be given to supplementary evidence provided by the claimants’ own physicians and carers. In many cases, the wrong decisions are damaging the work done by the community mental health teams, thus costing further resources.

An adviser from a community mental health team was very concerned when one of her clients had been found to not have limited capability for work. She described how he was so manic that it was impossible for him to sit down for more than a few minutes. He had given full details of recent hospital admission in his ESA50 but this was not followed up by medical services.

We believe it is essential that the exemption for those with a serious mental illness is restored and that expert evidence from community mental health teams is sought through an ESA113 rather than issuing ESA50s to clients. Decision-makers would still have scope to allocate claimants to the work-related activity group based on the advice of the mental health professional.

Short-term special circumstances

A further consequence of the current process is that some people are found fit for work when they are experiencing significant trauma – which may be temporary, but devastating; or they may be coming to terms with dramatic changes in their circumstances. Bureaux evidence shows that clients in these situations would expect to work again, but are not emotionally fit to actively seek work at the time of assessment. They are in real need of the support offered by ESA during the period of recovery, but decisions often fail to reflect this need, as in the cases below:

A Yorkshire bureau reported seeing a client who had had bowel cancer. He had had a colostomy and a stoma fitted and was having to change his stoma bag up to 16 times a day. He was undergoing investigations because he was losing a great deal of weight as food was going straight through him, which left him constantly exhausted. At the WCA he honestly explained all of this, but admitted that he could probably still walk 200 metres. He was found fit for work. The bureau found it hard to understand how the HCP could not have noticed how ill this client looked and how impossible it would have been for him to think about working or looking for work at that very stressful time.

A man in his twenties from the North West had recently been diagnosed with
a leaky heart valve sufficiently serious for him to require open heart surgery. He had been warned in the meantime that he should not work. While awaiting the open heart surgery he was found capable of work. He was struggling to come to terms with his medical condition and found the strain of this decision added extra stress.

A bureau client in the South West was experiencing reactive depression after breast cancer and a mastectomy. She found it very difficult to cope with what had happened to her and her altered body. Her husband had also found it hard to cope, and their marriage had broken up. She had a job to go back to that she enjoyed, but did not feel able at that point to cope with work. She was found fit for work.

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We believe that decision-makers should be given the discretion to take account of exceptional circumstances which indicate that the claimant is likely to return to work, but is not immediately ready to do so. They should have the power to make a decision for a short period on the basis of written evidence from the claimant’s own doctor.

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Hurdle two – Does the WCA have sufficient flexibility and range?

Popular myth and press reports suggest that too many people on IB were judged unable to work when they could work, so the criteria needed to be harsher. We agree with the principle that those who can work should work, but we consider identifying fitness for work to be a complex process, involving the condition itself, the specific impact on the individual and the work environment. It was clear to bureaux advisers that even under IB, there were many people found capable of work whose disabilities or illnesses effectively prevented them from finding work. In March 1997 we published a report pointing out that we considered the test used to assess someone’s entitlement to IB was seriously flawed. What is needed is not a harsher version of the same tool, but a more sophisticated tool. We do not think that the WCA provides a more sophisticated test, and we have identified a number of problems in its design:

- It takes little account of variability in symptoms.
- The descriptors should be more than additive.
- It takes no account of generalised pain and exhaustion which affects overall functioning, rather than having a significant effect on one aspect of functioning.
- It takes no account of the social model of disability.
- The guidance for the HCPs should be more appropriate.

Variable symptoms

In principle, the WCA should account for variability in condition, but variability of symptoms is not well accounted for. Many conditions such as multiple sclerosis (MS) have a number of symptoms but of a fluctuating nature, which affect people differently at different times. Someone may find that about 20 per cent of the time their walking is badly affected, while at other times their hands, sight or speech may be worst affected, or they cannot move their arms. None of these factors on their own may occur enough to achieve the required points in the WCA.

A client from a Yorkshire bureau reported that she had worked for as long as she could after being diagnosed with MS, but the effects became so disabling that she had to stop work.

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7 Citizens Advice (1997), An unfit test
8 See appendix for an example of comparative descriptors for PCA and WCA
This was a difficult decision as she loved her job, but she felt exhausted after very little exertion. She described this feeling of exhaustion to be unlike anything she had experienced before – well beyond tiredness and leaving her unable to think straight or do anything at all. She explained that some days she could walk 50 metres but she would then be completely exhausted – other days she could barely walk at all. She went through a period when she could reach with difficulty, but then found she couldn’t reach at all. The WCA did not seem to cope with the subtleties of her condition, and the report seemed to underplay all her problems.

The WCA does not look at the combined effect of low level problems or, alternatively, at problems which are serious but where each one is a problem for only a minority of the time. Yet the combined effect of these problems can make it impossible for someone to work. Although the PCA had similar limitations in dealing with variable symptoms, it was at least possible to achieve three points for lower level problems including walking, standing, reaching, lifting, dexterity, continence and others, which could then be added into a representative total. In the WCA a client may fit each of the more severe descriptors, say, for one day a week, but in different ways each day. Although overall the client would effectively be severely disabled, s/he gains no points in the assessment.

The guidance for health care professionals on variability

The guidance states that “For conditions which vary from day to day a reasonable approach would be to choose the functional descriptors which apply for the majority of the days.” For those with variable conditions this is not reasonable. Someone with a variable condition may be fit for work on their better days, but if, on their bad days (perhaps two or three days a week), they are housebound – or even bedbound – they will not be able to undertake full-time work, especially as they are unlikely to be able to predict which days they will be incapable.

In a fibromyalgia case decided by the US federal court in Washington\(^9\) it was ruled that:

“….the following picture emerges: a man who is continually drowsy and fatigued, unable to concentrate, unable to perform the most simple physical tasks, unable to stand, sit or walk for more than an hour at a time, unable to work more than 15 hours per week and unable to predict what hours he will be available, if at all. This court cannot imagine any occupation that such a person could fill successfully, much less an employer who would be willing to hire him.”

The design of the WCA needs to ensure that decision-makers can take such a holistic approach where relevant.

The descriptors should be more than additive

Evidence\(^{10}\) clearly demonstrates that when someone has more than one condition, the combined effect is often substantially greater than a simple sum of the factors, but the WCA takes no account of this. Someone who has mild learning difficulties and the sort of physical problem that limits them to walking 200 metres, is not likely to score enough points to be found eligible for ESA, but is likely to have great difficulty finding a job they can do, and would need considerable support to find and adapt to work.

A Midlands bureau saw a client with severe anxiety as a result of domestic violence. She also had osteoarthritis and was illiterate and innumerate. The barriers this woman faced in finding work were clearly greater than the sum of the parts. She was awarded no points in the WCA, but the combination of problems presented huge barriers. Her

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9 Ellis v Egghead (1999), Software Disability Plans
10 Mental-physical comorbidity and its relationship with disability: results from the World Mental Health Surveys, (2009), Scott et al, Psychological Medicine, 39, 33-43
adviser said it was “inexplicable how anyone could consider she is fit to actively seek work”.

Pain and exhaustion

The WCA has specific descriptors, but does not assess the underlying cause of the difficulty nor the overall impact on functionality, even though many conditions cause generalised pain and exhaustion which may cause difficulties beyond the descriptors. For example, someone may have an ankle problem which causes great difficulty when they walk but causes no problems beyond that. If they can only walk 30 metres because of the pain, they will be found incapable of work. In contrast, if someone has a condition which causes them to become exhausted after small amounts of exertion, they will probably only score points under the walking and standing/sitting descriptors, and will not reach 15 points. Pain caused by, for example, severe and frequent migraines or shingles may not be captured by the descriptors, but may cause great difficulty in concentration, and in practice make work impossible. So the generalised exhaustion or pain – especially if it is variable – may have a much greater effect on the client’s ability to work than the descriptors would indicate.

A man from Birmingham, with MS, was awarded no points and found capable of work. His functional capacity varied from day to day but any activity tended to leave him exhausted. He explained this to the HCP but he was still recorded as able to do the descriptor, and the fact that he couldn’t repeat it was not recorded, and nor were the effects of the exhaustion on concentration and other activities.

A client of a bureau in the North East suffered from severe facial pain. He found it very difficult to concentrate on anything but was found capable of work.

Social model of disability

The assessment takes no account of how the illness or impairment affects a particular individual’s chances of finding work in the actual context of the workplace environment, such as the following factors:

- The practical impact – for example a claimant with a lifetime of manual work will find that a physical impairment causes a much greater barrier to work than for someone with a greater physical impairment who also has high literacy levels and could work in more flexible situations. Because of the nature of the WCA, however, the manual worker may be found ineligible for ESA, while the other continues to receive the benefit.

- Adapting the workplace will be seen differently by employers depending on the level of skills the employee offers: while employers may see it as a reasonable adjustment to pay for extra support – such as a signer – for a deaf person who is highly qualified, few will see the same measure as a reasonable adjustment for an unskilled deaf person on the minimum wage.

- The barriers the person might face in travelling to work, or to sign on. Someone may be able to work from home, but if they are found ineligible for ESA and have to claim JSA, they will have to sign on at a jobcentre every fortnight. The assessment appears to assume that functionality for work includes the ability to use public transport. For clients in rural locations, for example, or with specific disabilities, public transport can be more of a barrier than the workplace itself. A visit to the jobcentre may involve four bus journeys for the round trip to a different town, with associated waiting and considerable walking to and from bus stops. The descriptors do not account for this.

- The impact of employers’ prejudices on people’s chances of employment. Research by the Chartered Institute of Personnel and Development (CIPD) discovered that “more
than 60 per cent of employers said they disregarded applications from people with drug or alcohol problems, a criminal record, a history of mental health problems or incapacity. More than half of respondents said nothing would persuade them to recruit from these ‘core jobless’ groups. Furthermore, research carried out by Rethink highlights the fact that fewer than four in ten employers would consider employing someone with a history of mental health problems.”\(^1\)

A bureau in Yorkshire reported a case of a client who had sustained an injury to his hand and also had a problem with his foot which made it difficult for him to stand or to walk long distances. He also had a minor learning disability. He had done manual work all his life up to the point he had injured his hand and foot. He was given six points for his problems with standing but no points for any other descriptor. The CAB reported that he was clearly going to have great difficulty finding work. The injury to his hand and foot had had a much greater impact on his ability to find work than a similar injury would to someone with higher educational qualifications.

We recommend that the assessment should have two stages. Capacity for work should be tested initially by functional ability, and if the impairment reaches the prescribed level – as in the current WCA – the claimant should be automatically awarded benefit.

However if functional capacity is higher than the prescribed level, so the person does not automatically qualify for benefit, there should be a further, ‘real-world’ test, based on the social model of disability.

The appropriateness of the guidance

There are some areas where the guidance to HCPs on the descriptors may contribute to why there are so many problems – for example, the walking descriptor gives no points to those who can walk further than 200 metres as outlined above, but the way that distance is calculated may not reflect the reality for the claimant:

A client was asked if she ever went to the supermarket. She responded that she did sometimes go with her husband if it was a good day, but was not allowed to explain more than this. She explained to the bureau that it was a very small supermarket and she only went up a couple of short aisles. She was staggered when she saw her WCA report and found that the HCP had used this as evidence that she could walk 800 metres.

Bureaux clients are frequently amazed by some reports on how far they can walk. The following guidance for the HCP may go some way to explaining this (though the phrase “easily manage” can be variously interpreted).

“Bear in mind that a person who can easily manage around the house and garden is unlikely to be limited to walking less than 200 metres; a person who can walk around a shopping centre/supermarket is unlikely to be limited to walking less than 800 metres.”\(^1\)

The guidance covering those with mental health problems or a learning disability might also indicate why bureaux see so many problems in these areas – for example, in the descriptor (c) covering learning or comprehension in the completion of tasks (LT), the customer would be awarded nine points if s/he fulfilled the following descriptor:

“Needs to witness a demonstration of how to carry out a simple task, before the person is able to learn or understand

\(^{11}\) CIPD (October 2005), Labour Market Outlook: Survey Report Summer/Autumn 2005

\(^{12}\) ESA Handbook for Approved Doctors, DWP
how to complete the task successfully, but would be unable to successfully complete the task the following day without receiving a verbal prompt from another person.”

This descriptor would appear to cover someone who might have difficulty learning a new task at work, which should mean they are awarded nine points. While this would not, by itself, find them eligible for benefit, if it were combined with a physical problem, the client would (appropriately) be awarded 15 points. However this is not necessarily what actually happens, as this example shows:

A bureau adviser in Yorkshire was surprised to find that a client who attended a special school, who could not read or write and who clearly found it difficult to grasp instructions was awarded no points under the descriptors intended to cover those with learning difficulties. He also had a physical problem for which he was awarded six points. The bureau believed that the combination of a physical problem and his learning difficulties made it very difficult to envisage any work this man could reasonably tackle without a great deal of continuous support.

The guidance for this set of descriptors may offer some explanation as to why he was awarded no points:

“Consider basic functions of personal care such as brushing teeth. This would involve remembering to put toothpaste onto a brush and brushing all areas of teeth. This may be regarded as a simple task. Other aspects of personal care may be the ability to be able to get up, showered, shave, clean teeth, select clothing items and get dressed appropriately for the weather outside. This may represent an ability to understand and retain information.”

Learning how to brush one’s teeth is a rather strange example of whether someone is capable of learning a new task, since most adults will have been brushing their teeth all their lives. An example of more relevance to the labour market would be more appropriate.

In descriptor 14 – Memory and concentration (MC) – descriptor (c) awards six points if the client:

“Frequently forgets or loses concentration to such an extent that overall day to day life can only be successfully managed with pre-planning, such as making a daily written list of all tasks forming part of daily life that are to be completed.”

Clearly many of us need shopping lists, but there is vast difference between needing a shopping list and the suggestion of the guidance that:

“In MC(c), the lists do not reflect the type of lists that could reasonably be expected to be utilised by those with normal cognitive function such as shopping lists. The descriptor reflects a need to have additional input to manage all tasks involved in daily life such as remembering to get washed and dressed.”

Forgetting to get dressed in the morning is an extreme sort of memory loss and clearly ought to be awarded more than six points. How many employers would take on someone who forgot to get dressed?! Remembering appointments and people who are due to visit would seem a more appropriate level of problem at the six point mark, than remembering to get dressed.

In descriptor 15 – Execution of tasks – (c) looks at whether the claimant:

“Takes more than one and a half times but no more than twice the length of time it would take a person without any form of mental disablement to successfully complete an everyday task with which the customer is familiar.”
Again, the guidance seems to illustrate the descriptor with an extreme problem — to the extent that it actually changes the meaning of the descriptor:

“The pattern of typical day activity should really reflect a person who would struggle to get through the basics of a day due to their mental disablement as a result of tasks taking so long to complete that they would be unable to cope with work due to the length of time required for basic tasks. For example those who have severe and continuous disabling anxiety where they struggle to even get out of their bedroom may come into this category.”

While the guidance offers these examples as a guide, it appears that they are being taken over-literally by some HCPs, and that by offering extreme cases, the guidance is leading to less extreme — but still debilitating — cases being under-assessed.

The guidance needs urgently reviewing and should include borderline rather than extreme examples to help clarify where the dividing line lies.

Hurdle three – Is the WCA applied effectively?

We understand the HCPs are expected to conduct eight to ten assessments per day. Atos Healthcare (the private firm employing the HCPs who conduct the medicals) states that the average length of an assessment is 45 minutes per claimant, but the majority of medical reports in appeal papers, seen by bureau advisers, are under 45 minutes. We have many reports from clients describing hurried medicals, in which the HCP does not look at them but at a computer screen. Clients do not routinely see the WCA report, and they are often shocked if they go to appeal, and then read the report in the appeal papers. One CAB client was given 0 points at a test, was mistakenly called for a second test, and was awarded 15 points although his condition was unchanged! Typical problems are outlined below:

Accuracy of the medical history in the report

The history taken by the HCP together with the customer’s account of a typical day should be an accurate reflection of what the customer reports. Later in the report, the HCP has the opportunity to reflect on the customer’s account, and to add their own comments. Clients only see this report if they request it, or if they appeal and their appeal goes to tribunal. Our clients are often astounded at the number of inaccuracies, distortions and missing key facts found when they read their medical histories. Several examples follow:

A bureau in the South East told us about a client who was a recovering alcoholic with mental health problems. He had twice attempted suicide. During the assessment he became very tearful, so the doctor terminated the interview and told the client not to worry. He was found fit for work. The client’s wife who was present during the test said the report was extremely inaccurate and contained much that the client simply hadn’t said. His consultant psychiatrist agreed with the client about how poor the report was and suggested he complain, but the client was worried about making a complaint. The stress caused by this led him to start drinking again.

A client from the South West was very surprised when she read her medical history. It started with a factual inaccuracy — it claimed that she had been diagnosed two years before, when it was actually four years before, and a letter had been provided confirming this. Far more seriously, it took no account of repeatability or variability. The HCP took an account of a really good day when she was able to go out, and described it as if it was an average day.
Common distortions

Some reports do not reflect the situation described by the claimant:

A client in the South West who had a serious heart condition which meant she was unable to walk more than 18 to 30 metres before experiencing great pain and breathlessness, was very surprised when she found that in the medical history it was recorded that she took their dog for a walk for 10 minutes or so every day, and this was used as justification for finding she could walk much further than she actually could. She had been asked about daily activities and had explained that when well enough she was driven by her husband to the park and she would sit on the bench right next to the place where they parked, while her husband walked the dog. The same report also recorded that she had been off work ill for two months when she had explained that she had actually been unable to work for two years, with her condition gradually worsening. She had finally accepted she would be unable to return to work two months before, so that was when her contract had ended.

One claimant explained that his report said “the client is actively seeking work through Jobcentre Plus” – what he actually said was that he was attending work-focused interviews which he had to do or risk a sanction.

Assumptions made

Although the HCP guidance states that open questions should be used, clients report that the questions tend to be closed. If clients try to offer an explanation they frequently say that they are not allowed to elaborate. They assume that the HCP has understood, but are often horrified by the assumptions that have been extrapolated from their answers.

A client from a Yorkshire bureau was asked what he was interested in, and said he used to enjoy motorcycling and still took an interest – watching DVDs and going to meetings of the motorcycle club. He was astonished when he read his medical history that it recorded him as enjoying riding his motorbike and then drew assumptions about what he was capable of doing on the basis that he could ride a motorbike. He had had to give up riding his motorbike because of his condition, but he liked to go to the club when he could and had to go in his car.

A bureau in the South East reported having seen two separate WCA reports where the HCP had recorded that the client watched television all day. In both cases the adviser – who is part of a community mental health team – was aware that the clients did not own a television. In both cases it appears that the HCP made assumptions about what the client did during the day without asking the question.

Full answer not recorded

Clients do not always feel they have been given time to develop their answers to questions, or they find that what they said has not been fully recorded:

A client with serious mental health problems was asked by the HCP if she had been offered counselling. He recorded that she had been offered counselling but had refused. However he did not record the full answer that she had had a very bad experience of counselling in the past and that it had opened up a number of things she couldn’t face at that time, so she didn’t feel able to cope with counselling when it was offered again.

Failure to observe accurately

Advisers sometimes find it hard to reconcile their knowledge of their clients with what is written in the WCA reports:
A client in East Yorkshire with drug and alcohol problems had been on a non-reducing methadone programme for five years. He regularly saw a consultant psychiatrist and a mental health counsellor. The HCP reported this as a very minor problem, saying that there was no smell of alcohol and that the client was well-dressed and clean. The bureau advisers were very surprised as he regularly came to the bureau and there was always a smell of alcohol, as well as clear signs of problems with personal hygiene.

A client in Yorkshire reported that the HCP had to take off her shoes and socks for her and put them back on again. However when she read the report she found that the HCP had said she had no problem with bending.

A client with high frequency deafness was reported by the HCP to have heard his name when it was called in the waiting room, and so was awarded no points under the hearing descriptor. The client pointed out that his wife had told him he was being called. The judge at his tribunal made a point of writing a statement of reasons even though one hadn’t been requested, and pointed out that it was clear the client could not hear across a table in a quiet room.

A client who described difficulty going up stairs, and even more going down, was reported to have had no problem with the stairs. The HCP had stated this in a way that would lead to the assumption that he had observed it to be no problem, but he had not actually observed the client climbing the stairs. The client had had to stop twice on the way up and had even more difficulty going down, but the assumption appears to have been made that because he made it to the assessment room, he had no problem.

Lack of understanding of criteria

Bureaux see other examples where the HCP has clearly misunderstood the criteria, leading to great hardship for clients:

A client had a stoma fitted after treatment for cancer. He had frequent loss of control of liquid from the bowels, but was awarded no points and the HCP put a line through all continence descriptors.

A client with poorly controlled epilepsy provided her ESA50 a diary with a detailed description of her petit mal seizures and their frequency. She also gave contact details for her consultant, but the consultant was not contacted and she was awarded no points for the appropriate descriptor. The HCP clearly did not understand what was meant by altered consciousness.

Atos states that its customer service surveys show good results, including for questions such as: ‘Did the HCP listen to you?’ Our experience is that our clients frequently believe that the HCP has listened to them and has understood their problems, but it is only when they see the WCA (or PCA) report (after they have completed the satisfaction survey) that they realise the problem.

A client of a bureau in Yorkshire had severe arthritis in her knees and was helped by her local CAB to apply for DLA. She was very surprised when she was turned down as she knew that her GP supported her application. She appealed and when she got the papers she was very surprised to see the reason for the refusal was her PCA report – the distance the HCP had estimated she could walk was far larger than she or her GP believed she could walk. She had thought the doctor doing the PCA had been very sympathetic and understanding and indeed he had given her sufficient points so she had been found incapable of work. However when
she looked at the report of what she had said, it was inaccurate and incomplete.

Some clients do not know that the report has inaccuracies, until they apply for DLA and are unexpectedly refused, despite support from their GP or consultant. When they appeal, they find that although they have been recognised as having limited capability for work, their WCA (or PCA) report has also been used to decide – and reject – their DLA application.

The WCA report should be routinely sent to claimants, who should be given opportunity and time to correct inaccuracies, in order to prevent further problems – and costs – later in the claiming process.

Or at the very least, regular surveys should be conducted to validate the factual accuracy of WCA reports.

Poor recognition of mental health problems

We have long been concerned about the poor recognition of mental health problems by many of the HCPs in the assessments. We see repeated evidence of people with severe mental health problems being found fit for work, and find it very hard to understand how people with clear and obvious problems are found to be suffering merely from mild depression.

A client who had attempted suicide a number of times in the past and was felt by his GP to be at ongoing risk was found to have mild depression by the Atos doctor and found capable of work.

A client who provided psychologist evidence of severe depression (PHQ 9) and severe anxiety (GAD 7) was given no points and found capable of work. The GP commented that she was “keen to work but detrimental currently”. The GP “supports [the client] being on

benefit” and commented that her mental health would be at risk if she were found capable of work.

Bureau advisers find that when there are physical problems as well as mental health problems, the mental health problems are even more likely to be under-estimated or ignored.

A bureau in the South West saw a client with both physical and mental health problems. The bureau reported that the client’s mental health problems were totally ignored in the assessment, and yet it was very obvious that there was a serious problem. When the bureau collected evidence for the appeal, the GP wrote that the client had a “severe mental health illness …” mentioned “referral to community mental health team” and added “also a significant suicide risk at present.”

A Midlands bureau saw a client with a long history of depression, as well as many other problems including back problems and diabetes, and who was also having investigations for possible epilepsy following a series of blackouts. The assessment only seemed to have considered the physical problems and the client was awarded no points. Yet at that point, the client’s mental health was causing more concern than the serious physical problems. The client had made three suicide attempts that year, still had suicidal thoughts, and was unable to go out of the house on their own. The bureau noted that the client had a social worker who confirmed all the details.

The following description by a claimant of what happened at his assessment is typical of countless examples from our clients:

“For most of the assessment the doctor sat behind a desk looking at a computer screen, reading from it and entering information. It was difficult to engage her directly in conversation or have eye
contact and I felt extremely alienated from the process. It appeared to me that the assessment questions followed the structure and content of the self-assessment form that I had filled in. This was in a file in front of her but she didn’t refer to it or the answers. Basically, she was asking the same questions over again. The questions and prompts she used were all closed, giving at most a choice between two alternatives which were frequently not relevant. Most of my assessment focused on my physical health which has never been an issue. She seemed unduly interested in a cardiac problem I have, but seemed unfamiliar with the drug that I take or the treatment I am about to have! I was anxious to explain in detail the effects of my depression on my life and work but this was very difficult. In part she had difficulty understanding me, but it was also clear that the on-screen questions did not allow for this. She seemed under pressure to complete all the questions whether or not they were relevant and my trying to explain things just got in the way. At various times she appeared to have difficulty navigating the screen and entering information. After approximately 20 minutes, she told me that we were running out of time. When I pointed out that the leaflet sent to claimants states that they can expect the assessment to take 75 minutes to 2 hours she became very upset and told me that staff were told to complete assessments in 40 minutes. The assessment ended with a desultory physical examination. The whole experience was frustrating and stressful. It was a bit like going into the bank to apply for a loan and you sit there while the bank clerk fills in an online application form.”

A client was asked by the HCP whether she went to the supermarket. This particular client was very withdrawn and had great difficulty going out of the house at all. She eventually recalled that she had been to the supermarket in December 2008 (10 months prior to the test). She could recall the date because she was aware of how much worse she had become since then. This was recorded by the HCP as she was able to go to the supermarket. The same HCP asked about visitors to her house. She explained that she was having visits from her grandson as part of a therapeutic plan agreed with her GP, but the visits were fully supervised by his father, as she wanted to be able to do this but found it very difficult. This was recorded as “Enjoys looking after grandson.” Her GP wrote a detailed letter to be used as evidence for her appeal about how withdrawn she was and added “In terms of Atos assessment, it is interesting how above would impact on her social functioning has been ignored.”

**Conditions downplayed**

Another common problem with WCA reports, is that conditions frequently appear to be downplayed. If a client’s condition has been described by their GP as ‘moderate’ – based on tests, MRI scans, reports from consultants or other appropriate diagnostic tools – the HCP is very likely to describe it – based on a half hour interview – as ‘mild’. If it is described by the GP as ‘severe’ it will be ‘moderate’ in the WCA report.
When the ESA50 for a client from Yorkshire was completed, a report from her own GP was included. This report referred to “severe arthritis of both knees... significantly impaired mobility” and “severe pain”. The HCP recorded her condition as “moderate” and her as “not suffering from a physical condition that severely affects lower limb function.”

Referral for a repeat medical

Bureau advisers also express concern at the frequency of the assessment tests, and of ESA50s being sent to claimants, some receiving several while they are going through the appeal process:

An illiterate client seen by a bureau in the South West was unable to grip with one hand. His knees were crushed in an accident and his right leg was shorter than his left, while one foot was at 90 degrees to his leg. The client was in constant pain, but was found ineligible for ESA. The bureau helped the client appeal the decision and won. Three months later, however, the client was called for another assessment. The bureau pointed out that the client’s conditions were all permanent and adaptation to overcome significant barriers to work was extremely unlikely in this timescale.

Another client in the South West had angina and experienced mental health problems. When she went for her WCA she had an angina attack at the centre. The HCP was aware that she had had an attack in the waiting room but did not record it. Two days later she had another attack so serious that she was admitted to hospital. She felt that it was the strain of the process which had caused this attack. She appealed the decision to put her in the work-related group, won her appeal and was put into the support group. One month after the appeal she was horrified to find the whole process was starting again when she was sent a new ESA50.

In summary, bureau evidence shows that the assessment process is not working. Many seriously ill and disabled people are being found fit for work and therefore ineligible for the support of the benefit designed specifically to help them.

Outcomes for people claiming ESA who are found fit for work

There are a number of possible outcomes for someone who is assessed and found fit for work. Our concern is for those who are found fit for work, but who are unable to find work, and who are either ineligible for – or cannot cope with – JSA, so end up with no work and very little income. The National Autistic Society ran a survey of 500 people on the autism spectrum. They found that a third of them were neither in employment nor on benefit.¹³

A person found fit for work may:

- find a job and make a successful transition into work
- find a job, but the stress and difficulty of coping with work makes their condition worse: their GP signs them off and they reclaim ESA on the grounds that their condition has worsened

A bureau in the South West saw a man who had had severe arthritis and had just had both his hips replaced. He was still finding it difficult to cope and was also struggling with a stoma bag. He had previously had bowel cancer and had had a colostomy. Despite all of this he was keen to return to work but knew he couldn’t cope at that time. He went for a WCA, was found fit for work and his ESA stopped. He had no entitlement to JSA, but felt he needed to contribute to the family income, so felt he had no option but to try and return to work. He returned to work and fell, damaging his hip, so he was off work again, and

¹³ National Autistic Society (October 2009), Don’t Write Me Off: make the system fair for people with autism
Not working

waiting for another hip replacement. He was so stressed that he was unable to eat and lost five stone in weight, while the NHS has incurred the cost of repeating the hip operation.

- be entitled to means-tested benefits, sign on and receive income-based JSA (JSA(I))

- be entitled to means-tested benefits but fail to claim: some are too ill to cope with signing on at all. Some will find it physically very difficult to get to the job centre – the criteria for being fit for work don’t take into account the sometimes physically demanding journeys. Others sign on and receive JSA, but, again, their condition means they find it difficult to cope with the demands placed on them by the conditionality of the JSA regime. They give up and stop claiming benefit. The cases below show how loss of ESA leaves some clients on totally inadequate incomes:

A bureau in London saw a client with serious mental health problems, who had a social worker and a housing support worker, and was under the community mental health team and seeing a psychiatrist. Despite her psychiatrist saying she was incapable of work, she was found fit for work at a WCA. She continued to be so seriously ill that she was under the care of the crisis team (which involved daily visits) and was unable to leave the house when her appeal was heard. She was clearly unable to attend the hearing but was found fit for work in her absence, despite this having been explained to the tribunal chair. The bureau are taking this case to the commissioners but in the meantime this woman is having to manage on her DLA alone (a benefit designed to help with the extra costs of being disabled, not as an income replacement benefit) as she is completely incapable of signing on.

A bureau in the South East reported a 25 year old client who had experienced depression from the age of 17. He was an in-patient at a rehabilitation unit and had regular appointments with a psychiatrist and a counsellor. He claimed ESA but scored no points at the WCA. It was clear to the bureau adviser that he had difficulties in descriptors such as memory and concentration, execution of tasks, initiating and sustaining personal action, coping with change, getting about and coping with social situations. Without ESA, the client was living on what money his father was able to give him.

- have been receiving contribution-based ESA (ESA (C)), but not be entitled to contribution-based JSA (JSA(C)) or income-based JSA (JSA(I)):

The contribution conditions for ESA are less rigorous than for JSA, so many people who qualify for ESA(C) do not qualify for JSA(C). Even those who do qualify for JSA(C) will only receive it for a maximum of 26 weeks. JSA(I) is a means-tested benefit, so anyone who has other income, or savings of more than £16,000, or a partner with an income, will not be entitled to the means-tested benefit. Hence a large number of people are moved from ESA(C) to no benefit at all.

One bureau reported seeing a client with cardiomyopathy, who had been extremely ill and was put on the heart transplant list. She had fortunately shown some improvement and had asked to come off the list for three months while investigations were made. The consultant had agreed to this but had advised that she might need to go back on the list. She had been advised in the meantime that she should try to walk for about 20 minutes each day, but after this she was so exhausted that someone had to move in with her temporarily to look after her. She had a WCA just after she came off the transplant list, and was found capable of

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14 Child Poverty Action Group (CPAG) Welfare Benefits and Tax Credits Handbook, p754 for contribution conditions
work. The bureau believes that it is just bizarre that anyone could find someone in her position capable of work, but reports that she felt it would be too stressful to appeal, so she lost her benefit. She had a partner who worked, so was not entitled to any other benefit, even if she had felt well enough to sign on.

This situation affects a significant proportion of claimants, since no one with a partner who is working, will be entitled to JSA for more than a short period, if at all.

**Permitted work and the disability element of tax credits**

Claimants on ESA are entitled to do a small amount of work for a limited length of time without it affecting their benefit – this is called permitted work. Some people being found fit for work are losing access to a very helpful route into sustainable work through permitted work and the disability element of tax credits:

A Yorkshire bureau saw a young man who had experienced severe depression since he was at school. With the support of his family, he had made a number of attempts to work but each time he had had to give up after a few months and return to IB. He had been offered a small part-time job but wondered what would happen at the end of the year of permitted work, as he wasn’t sure after his previous experiences if he would cope with going into full-time work. He was surprised when the bureau explained to him that he could build up his work gradually over the course of the next few months until it was just under 16 hours, and at that point he would be eligible for the disability premium of income support, and would then be eligible for the disability element of tax credits if he worked 16 or more hours. The bureau supported him through this complex process and the last they had heard was that he was still in work a year or so later.

For the above client, this was a highly effective route into work, but ESA rules do not facilitate this mechanism. If someone is found fit for work, but is not truly work-ready, there is likely to be a period of time while they prepare for work. When they eventually find a job, because of the way the rules operate, the time lapse will mean that they will no longer be eligible for the disability element. Many people with an illness or disability can only work part-time, but without this extra help, part-time work is unlikely to be sustainable for people on minimum wages.

Thus, an extremely helpful route into sustainable work is being threatened by the way ESA is operating. The recent Marmot Review, *Fair Society, Healthy Lives* commissioned by the Secretary of State for Health on health inequalities, states “It is imperative that the system of benefits does not act as a disincentive to enter employment.” The disability element exists to support this purpose, but its purpose is being frustrated.

**Implications for the future**

The DWP has recently recognised the importance of providing more back-to-work support for JSA claimants, since many will face significant barriers to work because of an illness or disability. We welcome the fact that the Department is examining ways to offer personalised support for ESA claimants moving on to JSA, and is currently proposing an extension of the Pathways to Work programme to some JSA customers. This does not, however, offer a solution for some of the people highlighted above, who are found ineligible for ESA, and end up with neither work nor benefit. The research mentioned earlier in this report shows that “those who move off benefits but do not enter work are more likely to report a deterioration in health and well-being.”

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16 Waddell and Burton *op cit*
It is mandatory for Government to consider a health impact assessment of any new government measure, but we are not aware that DWP has carried out a health impact assessment for ESA. The Marmot review, *Fair Society, Healthy Lives*, states “Work is good – and unemployment bad – for physical and mental health, but the quality of work matters. Getting people off benefits and into low paid, insecure and health-damaging work is not a desirable option”. Given that one of the aims of ESA was to improve people’s health and wellbeing by not “writing them off”,

we recommend that a health impact assessment should be conducted as soon as possible. As well as comparing ESA with IB, it should also look at what would be the health implications of allowing more sick and disabled people to remain on ESA while being given help and support to look for work.

DWP has conducted an equality impact assessment for ESA. However it seems to be based on the assumption that ESA will lead to better employment outcomes for disabled people. While we accept – and welcome – that there will be improvements for some, our evidence suggests that others will lose their benefit. There is no mention in the impact assessment of what happens to those disabled people who are found fit for work and lose their benefit, but don’t find work. Yet this is likely to lead to lower chances of employment and poorer health outcomes.

The Marmot Review draws attention to the degree of health inequality in this country. People’s physiological age can be very different from their chronological age, which should have implications for ESA. It has been pointed out that people in some places are more likely to die on sickness benefit before they die. Unlike healthier citizens they will not be receiving any pension.

Conclusions

**Bureaux evidence shows that the assessment process is not working.** Many seriously ill and disabled people are being found fit for work and therefore ineligible for the support of the benefit designed specifically to help them.

We have examined three specific elements of the way ESA assessment operates, using case examples from bureaux. We conclude that:

**Seriously ill people are inappropriately subjected to the work capability assessment (WCA).** Under incapacity benefit (IB) if someone was seriously ill or had certain disabilities, information was sought from their own doctor and if the diagnosis was confirmed they were exempted from the assessment. Allowing exemptions from the WCA could still allow claimants to be placed in the work-related group where appropriate.

We recommend that exemption is also applied when a person is clearly unwell and their health is under investigation by health professionals, and when the claimant is temporarily unfit for work while they adjust to a traumatic experience or dramatic change in their circumstances. The claimant in this circumstance could be placed in the appropriate group for a temporary period.

**The assessment does not effectively measure fitness for work.** It does not take sufficient account of variable symptoms. There is little recognition of generalised pain and exhaustion, or the seriousness of an underlying condition. It takes no account of the context of the work environment, including a person’s education, skills and circumstances, or the discrimination they may face in looking for work, all of which can significantly affect the scale of the person’s barriers to work. The examples in guidance
for health care professionals (HCPs) – especially for the descriptors covering mental health problems and learning difficulties – suggest a level of disability which does not seem to be envisaged by the descriptor itself, and so will lead to fewer people being awarded benefit than would have been expected.

At present the descriptors are based on expert opinion. Further research is needed into the actual, real-world effect of different disabilities or illnesses on different types of employment, considering the skills and qualifications necessary for that employment. It would be useful for example to try to establish a threshold in particular disabilities/illnesses, for different types of employment, where, even with the best employers, most people would be unable to continue in that employment. This empirical evidence from the workplace, together with the expert opinion, would allow a robust ‘triangulation’ approach to the WCA.

**Application of the assessment is producing inappropriate outcomes.**

Citizens Advice and other organisations have been concerned for many years about the quality of medical assessments for benefits. We still hear repeated reports of rushed assessments, assumptions being made without exploration, inaccurate recording and poor recognition of mental health problems. Now the descriptors have become much tougher, this issue has been brought into sharper focus.

The quality of the tests could be assessed in line with standard good practice for assessing the validity and reliability of classification methods. As with any classification test, the WCA will have some false positives (scored more than 15 points, but should have scored 15 or fewer) and false negatives (scored 15 points or fewer, but should have scored more than 15). DWP does not appear to have done any evidence-based research to determine the proportion of false positives and false negatives arising in these tests. This could be measured by, for example, having a sample of ‘mystery shopper’ cases assessed and scored by a team of medical experts and then sent anonymously to be tested by HCPs. **We believe that the reliability of these tests should be independently measured as a matter of urgency.**

These problems create major difficulties for our clients and undermine the Government’s aims for ESA. People with serious illnesses and disabilities who could not reasonably be expected to work are being found fit for work. Other people who might, with considerable support, be helped into work, are effectively being “written off” by being found fit for work and therefore ineligible for ESA. Many of these people are too ill to sign on, or are not eligible for any other benefit, and so are left with no money and no help or support to find work. Furthermore, many of those found ineligible for ESA also lose access to an extremely helpful route into sustainable work through the disability element of tax credits.

**The Government’s declared aim is to improve people’s health and well-being but this report shows that ESA is not currently achieving this aim for some of the people who most need it. People moved off benefit but not into work are effectively moved further from the labour market, and risk poorer health outcomes.**

Our recommendations are set out in full at the beginning of this report.
## Appendix

One example of comparative descriptors for PCA and WCA – walking

<table>
<thead>
<tr>
<th>PCA descriptor</th>
<th>WCA descriptor</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Walking on level ground with a walking stick or other aid if such aid is normally used.</td>
<td>1. Walking with a walking stick or other aid if such aid is normally used.</td>
</tr>
</tbody>
</table>

### Descriptor points

<table>
<thead>
<tr>
<th>Description</th>
<th>PCA Points</th>
<th>WCA Points</th>
</tr>
</thead>
<tbody>
<tr>
<td>a) Cannot walk at all</td>
<td>15</td>
<td>15</td>
</tr>
<tr>
<td>b) Cannot walk more than a few steps without stopping or severe discomfort.</td>
<td>15</td>
<td>15</td>
</tr>
<tr>
<td>c) Cannot walk more than 50 metres on level ground without stopping or severe discomfort.</td>
<td>15</td>
<td>15</td>
</tr>
<tr>
<td>d) Cannot walk more than 200 metres on level ground without stopping or severe discomfort.</td>
<td>7</td>
<td>9</td>
</tr>
<tr>
<td>e) Cannot walk more than 400 metres on level ground without stopping or severe discomfort.</td>
<td>3</td>
<td>6</td>
</tr>
<tr>
<td>f) None of the above apply.</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

*Note: the PCA has a separate (but overlapping with walking) descriptor for climbing stairs.*