

Beyond the Barriers

A Spartacus network report into Employment Support Allowance, the Work Programme and recommendations for a new system of support.

Contributors : Stef Benstead BA (Hons) (Cantab), Sue Marsh BA (Hons), Caroline Richardson, Jamie Cartwright BA (Hons) (Cantab) MA MSc; Catherine Hale; Sam Barnett-Cormack BSc MSc

Thanks also to the hundreds of people who took part in consultations or contributed case studies through the Diary of a Benefit Scrounger website and other media.

Work for those who can. Security for those who can't. Support for all.

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Executive Summary

1. This report is a comprehensive analysis of the most relevant evidence available on Employment and Support Allowance (ESA), the Work Programme and the barriers to work faced by people with long term health conditions and disabilities.
2. The report draws on a wide range of international data, UK evidence and case studies as the basis for any conclusions, giving equal weight to academic research and individual experience. Case studies were taken from 5 consultations which received over 1,200 responses.
3. **We look at multiple factors that indicate ESA is not working and find that tests are inaccurate, inconsistent, unreliable and invalid.** Reliable means a test can be repeated and is consistent. Valid means a test accurately describes the real world. ESA is not reliable as it does not produce consistent results. ESA is not valid as reports are inaccurate and few claimants found fit for work do enter work, in comparison to claimants of Jobseeker's Allowance. There is urgent need to address the inaccuracy of assessments and decision making to produce an assessment that is reliable, and to address the descriptors and decision making to produce an assessment that is valid.
4. **We asked people what they felt was the worst aspect of ESA and work capability assessments (WCAs). The responses indicated that:**
 - 50% considered the worst part of ESA to be that it is a highly stressful process, frequently inducing fear in claimants;
 - 40% identified specific flaws in the assessment process as the worst part;
 - 30% expressed views that the process does not work;
 - 29% were concerned by negative attitudes towards those on sickness benefits;
 - 9% explicitly said that time-limiting is one of the worst things about ESA; and
 - 5% explicitly said that they consider ESA to have been designed to deny claims.

We found that:

- The points system, descriptors and computer system are incapable of gathering the reality and complexity of people's conditions;
- The descriptors do not capture a person's state of health in a way that reflects their ability to work;
- Medical evidence from those who have detailed, accurate and relevant knowledge is ignored;
- Assessors lack the time, ability and medical knowledge to assess and understand an individual's condition and how it relates to work;
- Decision makers lack the medical knowledge to make accurate and informed decisions; and
- The assessment is irrelevant to work, as no attempt is made to discover *what* work an individual is supposed to be capable of doing.

5. **The report analyses the government response to recommendations made by Professor Harrington in his independent Year 1 Review of WCAs (Nov 2010) and found that of 25 recommendations, almost two-thirds have not achieved success.** Three were not implemented at all; five were implemented with limited success; and eight were not fully implemented, which consequently also means a limited success. Whilst the government accepted all of the recommendations at the time, it is clear that actual implementation has been patchy and incomplete.
6. **The report considers a wide range of international data** from Australia, The Netherlands, Iceland, Norway, Denmark and Sweden, drawing on the most successful elements of each to make recommendations on how our own out of work sickness provision and work support could be improved.
7. **The report suggests an alternative to the current ESA system, recommending:**
- Early Intervention: Where a person becomes ill or disabled whilst in work, assistance should start within a few weeks of claiming Statutory Sick Pay, i.e. even before a claim for Employment and Support Allowance is made. If the person is not in work, then assistance should start within a few weeks of entering a claim for ESA.
 - That an ESA113 form or equivalent is sent out to a chosen healthcare professional at the start of every claim and that regulations 29 and 35 for current and ongoing ESA claims and Contribution-based ESA are considered in all cases where:
 - a) The claimant suffers from an uncontrolled or uncontrollable illness, or
 - b) The claimant suffers from some specific disease or bodily or mental disablement and, by reason 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/work related activity.
 - A supplementary payment for those not expected to work or move towards work also available to those who engage with future support.
 - That the criteria for access to sickness benefits should take into account the non-medical factors that interact with medical factors.
 - That assessment should explicitly focus on what work or job role the claimant is supposed to be capable of doing, what barriers exist and how these can be overcome.
 - That assessments should occur over several meetings with a consistent caseworker to reduce the snapshot effect and to increase the amount of accurate evidence collected.
 - Once the process of assessment is complete, evidence should still be submitted to an independent Decision Maker.
 - That the assessor have experience in the relevant disability
 - Multi-disciplinary interventions. An integrated system where the caseworker can advise on benefit entitlement, health services, social care, Access to Work, and has access to local and national information on work support provision, education and training.
 - Early access to health interventions and control of a Personal Health Budget.
 - Including the claimant's workplace in interventions where possible/applicable.

- Disability specific support.
8. Many of the suggestions for a new model of out of work sickness support will take time to implement. **Therefore the 'Interim Recommendations' section suggests a series of recommendations that would quickly make the system that already exists safer and fairer** whilst a new model can be developed and piloted. These include:
- Continuing to pay ESA whilst mandatory reconsideration is carried out, and setting a time limit for mandatory reconsideration to be completed.
 - For all assessment centres to be made accessible and home visits to be offered where appropriate when this is not immediately possible.
 - Setting minimum time limits on reassessments.
 - A Mental Health Champion in every assessment centre.
 - Removing the current division between cognitive and physical assessment.
 - For all WCAs to be recorded.
 - Early implementation of the Evidenced Based Review (EBR) and improved descriptors for mental health and fluctuating conditions.
 - Requesting evidence from healthcare professionals in all cases (ESA113) and for sections 29 & 35 to be used in all cases where the healthcare professional believes there may be risk to the claimant.
 - Ending the 1 year limit to contributory ESA for those in the work-related activity group (WRAG).
9. We look at the most up-to-date information available on the Work Programme and find that it fails to meet the needs of those with long term illnesses or disabilities. **Just 3.34% achieved a Job Outcome, while for those transferring from the previous Incapacity Benefit the figure is just 0.98%.** The Work Programme is less likely to result in a positive work outcome than the old Incapacity Benefit system. We found that:
- The conditionality regime does not address barriers to participation.
 - The support service does not refer to the claimant's assessment of needs.
 - There is an unhelpful conflation of disability with long term worklessness.
 - Disabled people's skills and motivation are often lost through the programme.
 - Conditionality can move claimants further away from work.
 - The Work Programme offers a poor level of customer service to often vulnerable claimants.
- We recommend that mandation of ESA claimants to the Work Programme in its current structure is ended immediately. We believe that clients should control their own back to work support budgets as they are best placed to assess what help they need, what barriers they face and what interventions might be necessary to return to work.**
10. The final section of the report looks at how the labour market is currently structured and how it can act as a barrier to sick or disabled people entering or keeping work.

We recommend several ways in which those barriers might be addressed:

- New structures for flexible working and working from home.
 - Re-structuring out of work sickness benefits and tapers to make sure that “Every hour Counts”.
 - More support for those living with long term conditions or disabilities to set up micro-businesses through co-operatives and pairing and practical ways that the state might support innovation and enterprise.
 - Improved information on and access to further education and training.
 - More employer engagement and more done to encourage m, incentivise or mandate the employment of sick and disabled people.
 - Improved childcare for children with disabilities and more support for parents with disabilities to fulfil their parenting role.
 - We look at contribution and suggest both a “volunteers credit” and a “carer’s credit”.
11. We provide more in depth analysis in the Appendices including literature reviews on existing evidence relating to working with long term health conditions and disabilities and a much fuller analysis of the Harrington recommendations.
12. We conclude that both ESA and the Work Programme are failing people living with long term health conditions and disabilities, and outline a blueprint for change based on existing evidence and the experiences of sick and disabled people themselves. Our proposals are workable, proven in other countries, and wherever possible we suggest existing schemes and structures that could be modified to accommodate a new way of working. **A system which works for sick and disabled people, while also creating value for taxpayers, need not be a contradiction in terms.**

Introduction

The need for this report could not be more pressing. It is now widely accepted that the current approach to reforming out of work sickness and disability benefits has achieved few of its objectives. Every day, more and more people are failed by a system designed to support them.

Without understanding what may have led to those failures, we cannot move on. Without listening to people who have experienced the current system, we fall into the trap of designing policy far removed from the lives and aspirations of those affected.

How do we define illness? Impairment? Disability? Who should qualify for support? How tough should the criteria be? Indeed, does being “tough” actually achieve the stated aims of a society working as close to full employment as possible, or is it counter-productive? Is work beneficial in and of itself, or are there important caveats we have failed to consider? Does the Work Programme offer the right framework for people with long term conditions, mental health conditions, learning difficulties and physical impairments? This report analyses the widest possible range of existing data in an attempt to answer some of these questions: not through ideology, but detailed examination of the evidence.

The report draws on the comments and feedback from 5 separate consultations and over 1,200 responses. We asked sick and disabled people what work – if any – they felt they could do, and in what ways they felt restricted by society, their impairment(s), or the current social security system. We asked them about the ESA process and how they felt it could be improved, and we asked them for their experiences of employment support through the Work Programme.

We analysed the recommendations made by Professor Harrington in his Year 1 Review of Work Capability Assessments, and his subsequent reports to provide a comprehensive analysis of how many of his suggestions have been enacted, how many have only partially succeeded and how many have not been done at all.

We also looked at other countries, to find out what lessons could be learned from alternative approaches to welfare reform.

But primarily, this report seeks to recommend ways that we can move forward. It is now clear that tinkering with a failing system has not significantly improved outcomes. Whilst more sick and disabled people now qualify for ESA, more also go on to appeal decisions they disagree with: and, in turn, more of those appeals are being upheld in law.

These failures are costing the taxpayer dearly – much more than could ever be saved through estimated fraud, yet we prefer to spend precious resources on a system that doesn't work, rather than listen to those who can show us where we're going wrong.

Of course, it is easy to produce a report that merely criticises the status quo, but much harder to propose solutions. Some may be obvious, but others require imagination and

ambition. In this report we outline an alternative structure to ESA based on extensive consultation and research, which we believe would create a considerably fairer and more effective system. We recommend that ESA claimants are no longer referred to the Work Programme, but control their own personal budgets for back to work support and we recommend ways to overcome some of the greatest barriers to work faced by people living with long term or degenerative illnesses and disabilities.

But any recommendations, however well designed or structured, can only ever succeed if the implementation is true to their intent. If those charged with carrying them through really understand the aspirations and limitations of the people they aim to help. If we truly believe that it's time to build a system of out of work sickness and disability support that inspires, enables and encourages, then it will take true co-production and great commitment.

The longer we put off making that commitment, the more potential we waste.

What's Wrong With ESA?

Summary

Employment Support Allowance isn't working. Any test that works has to be able to be repeated with consistent results, and has to produce results that accurately reflect the real world. Data and evidence from the test can be considered to provide information on its reliability and validity. There are multiple data and evidence that ESA does not work. These include:

- Inaccuracies in Atos reports;
- Variability in Atos assessments;
- Inaccuracy of guidelines for assessors;
- Variability in decision making;
- 42% success rate at appeal;
- A majority of overturned appeals overturned on new oral evidence; and
- Low employment rate of claimants 12-18 months after a decision.

1. Inaccuracies in Atos reports.

Welfare advisers and claimants frequently find inaccuracies in claimants' Atos reports, including:

- **Omission:** for example, an assessor not mentioning a claimant's medical condition;
- **Incorrect recording of observation:** for example, an assessor reporting that a claimant who could not sit easily could sit easily;
- **Incorrect recording of the history given by the claimant:** for example, an assessor reporting a claimant can dress unaided when they have said they cannot do so;
- **Incorrect medical evidence:** for example, an assessor reporting something which they are not in a position to accurately report on;
- **Information not being gathered:** for example, an assessor not giving a claimant time to answer, or asking closed questions;
- **Inconsistency within the report:** for example, one claimant was reported separately as having weekly and monthly hypo attacks; the latter was used – incorrectly – to determine points; and
- **Supporting medical evidence is ignored.** This can lead to inconsistency.

A study by Citizen's Advice found that 43% of reports included inaccuracies so serious that they could have impacted the final decision made. Over half of reports did not gather all information, while 70% included incorrect factual recordings of the history given.¹

Meanwhile, a study on the use of reconsideration by Decision Makers found that 17.3% of cases were referred back to Atos.² This contrasts with 0.22% that had been referred back to

¹ CAB, Right First Time, 2012.

² CAB, Right First Time, *ibid*.

Atos over the period 1 March 2011 to 31 May 2011. It is unclear if these two figures relate to the same or similar issue but if so it is concerning that they reveal a difference of two orders of magnitude.

The report made by an Atos assessor is not routinely returned to the claimant for comment. If it were, this would be an opportunity for claimants to correct inaccuracies.

2. Omission.

Omissions are particularly worth noting, as the primary reason why decisions are overturned is presentation of new oral evidence. Whereas documentary evidence may not have been available at the time of the assessment, oral evidence would have been available. The assessor should have been able to elicit this evidence by appropriate questioning and listening.

3. Variability in Atos assessments.

The Harrington Review's second year report included an analysis of the points awarded to claimants by assessors from different medical backgrounds. The Review found that doctors on average awarded more points, although this may be due to their assessing the more complex cases. Further work focusing on the 'simpler' cases would be useful, to see if doctors also award more points for these.

It was also found that nurses under-award points for claimants suffering from physical health conditions, and physiotherapists under-award points for claimants suffering from mental health conditions. These findings are concerning as they could indicate a widespread under-appreciation of medical conditions that are outside an individual assessor's field.

4. Inaccuracy of guidelines for assessors.

Several disability charities and organisations have reported that the guidelines given to Atos assessors are inadequate. The National AIDS Trust said,

*"All HCPs undertake training which includes a module on HIV and have access to reference material on HIV. However, NAT has seen these training materials and it is clear that these have not been prepared specifically for use in the WCA process. The majority of the information concerns diagnosis, prognosis and prescribing treatment for patients with HIV in clinical care settings, which is not relevant to the WCA. HCPs receive no information on HIV and work in the UK context, or the most common HIV-related barriers to work. Atos has so far refused offers from leading HIV organisations to provide advice to improve these materials."*³

The Muscular Dystrophy Campaign said,

³ National AIDS Trust response to Work and Pensions Committee:
<http://www.publications.parliament.uk/pa/cm201012/cmselect/cmworpen/writev/1015/esa15.htm>

“The lack of knowledge about neuromuscular conditions is highlighted in the Department for Work and Pension’s Disability Handbook... For example, the section on Becker muscular dystrophy categorically states that the condition does not affect the heart. This is simply incorrect—cardiomyopathy is a very serious complication of Becker muscular dystrophy. Furthermore the Handbook incorrectly describes the severity of muscle disease, providing misleading information for assessors, and needs to be revised and corrected as a matter of urgency.”⁴

5. Variability in decision making.

The Review noted in its first year report that the quality and consistency of decision makers varies between individuals and between benefit centres. Benefit centres vary depending on whether the manager focuses on accuracy and quality of decisions or on speed of decisions.

This means that ESA decisions are *not* consistent or replicable, an important measure of a test’s ability. ESA is designed to be objective and replicable; that is, the same evidence before different decision makers should lead to the same conclusion, and for the same clear reasons. Without this consistency, the validity of the assessment process is seriously undermined.

6. 42% success rate at appeal.

The latest data shows that for the past three quarters, 42% of those who took their ESA decision to appeal had the decision overturned in their favour. Moreover, people who have a representative have an even higher overturn rate, including:

- 70% at Citizen’s Advice Scotland;⁵
- 94% at Oxford Welfare Rights;⁶ and
- 100% at a London HIV organisation.⁷

It has been suggested that the reason for the higher overturn rate when a claimant is represented is due to a lack of understanding of how the appeal process works. At appeal, a judgement is made on whether the correct number of points was awarded, not on whether there is a general ability to work. Evidence from medical professionals and from claimants themselves does not always explicitly address the disputed points, and thus is not always suitable as evidence for lack of ability to work.⁸

A representative is more likely to work to explicitly address each descriptor and the points awarded, thus presenting a case that is more directly relevant to the appeal. Claimants may be losing their case because they were unaware of the format their presentation needed to take, not because they in reality do not meet enough descriptors to qualify for ESA.

⁴ Muscular Dystrophy Campaign response to Work and Pensions Committee:
<http://www.publications.parliament.uk/pa/cm201012/cmselect/cmworpen/writev/1015/esa29.htm>

⁵ Dryburgh, 2010

⁶ Oxford Welfare Rights written evidence submitted to Work and Pensions Committee

⁷ National AIDS Trust response to Work and Pensions Committee, op cit.

⁸ See Appendix 1 for quotes.

7. New oral evidence behind a majority of overturned appeals.

60% of ESA decisions that are overturned on appeal, and have a reason given for the overturn, are overturned because of “cogent oral evidence.” A further 27% are overturned on the same evidence but with a different conclusion reached.⁹

As a proportion of all overturned appeals – including those where no reason for the overturn was given – this works out as 39% with cogent oral evidence and 18% with same evidence but different conclusion.

Sheila Gilmore MP, speaking in her role as a member of the Work and Pensions Select Committee, said,

“It perhaps suggests that, indeed, the original process was not getting the information properly, if it was a face-to-face assessment – and this goes back to the question of whether the assessment is failing or not... When somebody goes to an appeal, which in many ways might be, I would have thought, more stressful and quite challenging for people, they are able to express themselves better than they appear to have been able – this is one hypothesis – at the assessment. The reason people have given for that is the very mechanical way – this goes back to the criticism that I think Glenda [Jackson MP] was trying to get at. I am not asking you to guess whether this is the cause for the 40% and the assessment was too narrow or somehow the judges are better at getting things out of people, but that surely shows just how important it is that we understand this process, because that is a large number.”¹⁰

There is good reason to be concerned if new oral evidence is elicited at the tribunal, as this should also have been elicited at the original face-to-face assessment with the Atos assessor. Given the inquisitorial nature of such assessments and tribunals, it may be considered a failing on the part of the assessor, the assessment, or both that this information was not elicited sooner.

8. Situation 12-18 months after outcome.

Claimants found fit for work are presumably judged to have health conditions that do not significantly disadvantage them or present significant barriers to work. If this were the case then these claimants should generally move into work at the same rate, or at a comparable rate, to people claiming Jobseeker’s Allowance (JSA).

80% of people on JSA leave within 6 months. Whilst not all of these move into work, it is believed that getting a job is the predominant reason for leaving JSA.¹¹

In contrast, only 25% of ESA applicants found fit for work are in employment 12-18 months later. This is substantially lower than the comparable figures for those leaving JSA. Figures

⁹ Social Security and Child Support (SSCS) appeals allowed: early analysis of the pilot study data, Nov 2012.

¹⁰ Work and Pensions Committee, ESA and the WCA, Oral and Written Evidence, 21 Nov 2012.

¹¹ Data available from www.nomisweb.co.uk

for people placed in the Support Group (SG) or Work Related Activity Group (WRAG) are similar at 10% and 9% respectively: possibly indicating that on average there is little medical difference between the two groups in terms of their ability to work.

These results suggest that the average person found to be fit for work is not fit for work, and that the average person placed in the WRAG is not closer to work than the average person placed in the Support Group. Either the assessment process has failed to award the correct points, or the descriptors are inadequate at capturing an individual's capability for work.

Conclusion

There are multiple indicators that ESA in its current form is not working. The assessment process is inconsistent – as shown by the frequent inaccuracies in Atos assessors' reports, the variability in decision making and the high overturn rate at appeal. The assessment itself is invalid – as shown by the low percentage of claimants who find work after a fit for work decision.

Even in a statistical understanding of the terms, ESA is unreliable and invalid. Statistically, a 'reliable' test is one which can be repeated and is consistent. A 'valid' test accurately describes the real world. ESA is not reliable as it does not produce consistent results; and not valid as reports are inaccurate and few claimants found fit for work do enter work, in comparison to claimants of Jobseeker's Allowance.

There is urgent need to address the inaccuracy of assessments and decision making to produce a means of assessment that is reliable. Furthermore, there is urgent need to address the descriptors and decision making to produce an assessment that is valid.

Case Studies and Consultation

“... there is no support - you've been thrown away regardless, and none of it was ever about illness, disability, ability or recovery: for them it was always only about the money. And they keep insisting we're not cheap, but I feel cheap.” – Respondent to ‘Diary of a Benefit Scrounger’ consultation

Summary

In March 2013, a consultation was run through the ‘Diary of A Benefit Scrounger’ (DOABS) blog, asking readers to leave comments detailing what they considered to be the single worst aspect of ESA.¹² The responses were as follows:

- 50% considered the worst aspect of ESA to be that it is a highly stressful process, frequently causing fear in claimants;
- 40% identified specific flaws in the assessment process as the worst part of ESA;
- 30% expressed views that the process does not work;
- 29% were concerned by negative attitudes towards those on sickness benefits;
- 9% explicitly said that the time-limiting is one of the worst things about ESA; and
- 5% explicitly said that they consider ESA to have been designed to deny claims.

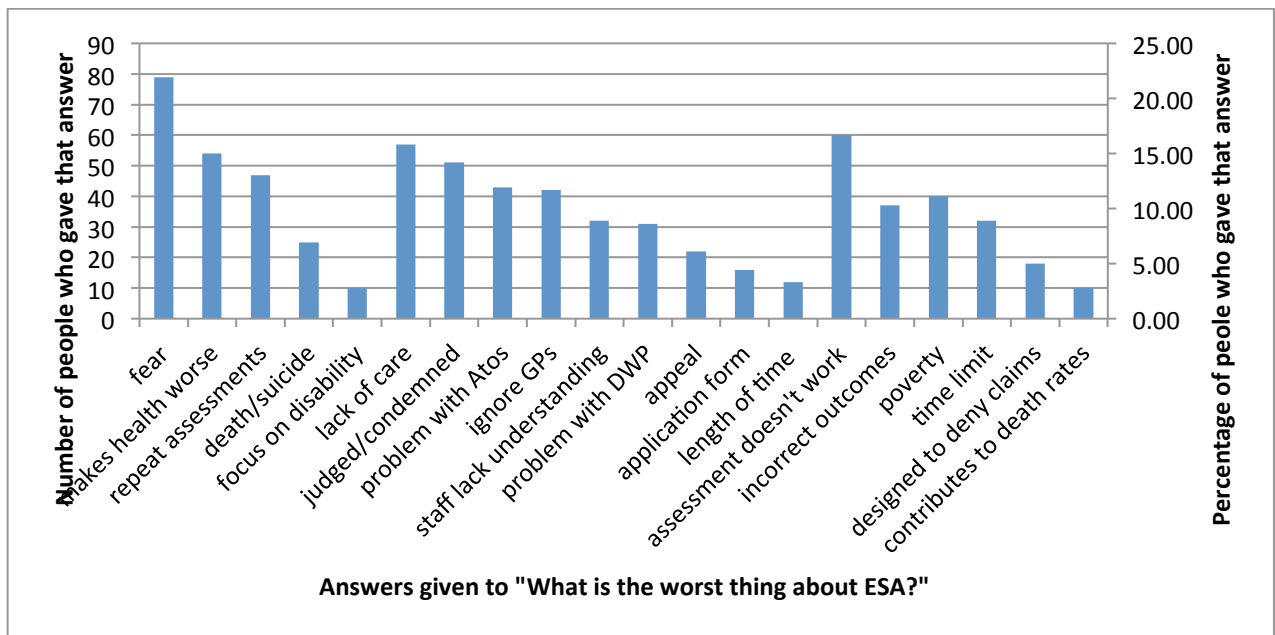
These responses reveal the huge amount of fear amongst the disabled and chronically ill community that is generated by ESA, its assessment process and general attitudes amongst the media, politicians and society in general. ESA is overwhelmingly regarded as not working and not fit for purpose. It is considered that:

- The points system, descriptors and computer system are incapable of gathering the reality and complexity of people’s conditions;
- The descriptors do not capture a person’s state of health in a way that reflects their ability to work;
- That medical evidence from those who have detailed, accurate and relevant knowledge is ignored;
- The assessors lack the time, ability and medical knowledge to assess and understand an individual’s condition and how it relates to work;
- Decision makers lack the medical knowledge to make accurate and informed decisions; and
- The assessment is irrelevant to work, as no attempt is made to discover *what* work an individual is supposed to be capable of doing.

A system that works would need to address all of these issues.

¹² <http://diaryofabenefitscrounger.blogspot.co.uk/2013/03/esa-sos-starting-gun.html>

Figure 1.1: Answers Given to 'What is the worst thing about ESA?'



1. FEAR

Many people have expressed fear and dread in relation to ESA. Uncertainty regarding outcome, coupled with high frequency of assessments, leads to insecurity – claimants, however ill, never feel sure that they will get or keep the support they need. Many of the responses included elements of fear alongside or as a consequence of other issues.

“The worst thing about ESA/WCA is the fear; the fear that an assessment form may come through the door any day, the fear that the subsequent face to face assessment will be wrong, the fear of the appeal & trying to exist on 'assessment rate' pennies for over a year until tribunal.”

1.1 Stress makes health worse

Community mental health teams have expressed their concerns that ESA is damaging their clients’ mental health, where previously under IB the involvement of the community MHT would be considered indicative of the severity of the claimant’s condition.¹³ A survey carried out by the Disability Benefits Consortium found that 78% of claimants agreed that the assessment process made their health worse; this was an increase from 69% in the previous year.¹⁴

“Time and effort filling in forms invariably takes physical and emotional toll even when result is "good". I am ALWAYS ill as a result of a reassessment.”

1.2 Stress of repeat assessments

¹³ CAB advice on ESA

¹⁴ Disability Benefits Consortium, 2012

The government has said that everyone on ESA will be reassessed at least every 2 years, even where there is no expectation of recovery or adaptation, in order to ensure that no-one is completely written off.¹⁵ This has resulted in fear and insecurity for claimants who, despite experiencing no change or even a deterioration in their condition, cannot guarantee that they will remain in either the WRAG or SG in future assessments. “Almost 90% [of welfare advisers] believed the frequency of reassessment was having a negative impact on the health of claimants.”¹⁶

“No matter how ill and weak, you have to constantly battle -revolving door process, no security, just WCA, claim ended, appeal, win ... WCA ... and now we have the mandatory review ...”

“The worst thing about ESA/WCAs is the ongoing stress of assessment. I have been diagnosed with a long term chronic health condition with no cure, and which is made worse by stressful situations, yet have to be assessed every year or two and despite filling the form the same way every single time, the response can be totally different.”

(TRIGGER WARNING **)**

1.3 Beyond breaking point

The website ‘Calum’s List’ contains names of 30 people who have died, where the death has been linked to welfare. Nine were cases where the family believe stress triggered the death; twenty where the person took their own life.¹⁷ 7% of responses to this survey cited suicide as a consequence of, or as a logical, sensible or sole available response to the stress of ESA.

“The fear that it will drive my son to another suicidal mental breakdown and I won't have the strength to save him this time as I've become disabled myself through being his carer.”

1.4 Forced to focus on disability

Whilst ESA is supposed to be about capability, not incapability, it is necessarily the case that by thinking about what one *can* do, one thinks about what one *can't* do and the reasons why not. Given that such a focus is unavoidable, it is crucial that the assessment process is designed with kindness, compassion and consideration in mind. This is particularly important in instances of trauma or abuse.

“Having to prove over and over again that you have many problems that are not going to go away is crucifying.”

¹⁵ Mark Hoban, Hansard: 19 Dec 2012, Column 784W

¹⁶ Disability Benefits Consortium, 2012

¹⁷ <http://calumslis.org/>

“The worst thing is having to relive every psychotic episode while filling in the form, every abusive put down, every single personal detail when I hate revealing personal details about myself to anyone, driving me to psychosis, the WCA is biased against mental health conditions.”

2. LACK OF CARE WITHIN THE SYSTEM

2.1 Lack of care

16% of respondents referred to the ESA system as inhumane, cruel or otherwise uncaring. There is a widespread perception that there is no official concern about the individuals undergoing the assessment, within either the Department for Work and Pensions (DWP) or Atos. This is compounded by widespread media rhetoric and government portrayals: whether expressed through imagery of ‘workers/strivers’ versus ‘shirkers/skivers’, or through the kind of dismissive attitude displayed by Iain Duncan Smith MP when he spoke of Remploy workers as “not doing any work... just making cups of coffee.”

“That this government refuses to face the facts or that these are real people not just numbers.”

“Knowing the whole process was designed by people like [Lord] Freud who labels, categorises and dismisses us all as “Stock”, thus seeking to strip us of our dignity.”

2.2 Feel judged or condemned

There is general support amongst the public for giving benefits to sick and disabled people.¹⁸ However at the same time there is widespread belief that a high proportion of claims are not genuine.¹⁹ The consequence is that many genuine claimants feel judged as cheats or “scroungers” by a public who do not understand the reality of their situation. Media use of pejorative language towards the sick and disabled has increased recently, contributing to the ‘climate of fear’ felt by many.

“The worst thing about ESA, being made to feel that due to no fault of your own that you are an unnecessary burden on society despite paying into the system for 30 odd years.”

3. PROBLEMS WITH THE ASSESSMENT PROCESS

3.1 Problems within Atos

3.1.1 Tick-box based computer system

Atos Healthcare, the company contracted by the DWP to carry out Work Capability Assessments, uses the computer program ‘Logic Integrated Medical Assessment’ to record information obtained during the assessment. The program includes drop-down menus

¹⁸ British Social Attitudes Survey 30

¹⁹ Survey for the Royal Statistical Society and King’s College London, as reported in Paige, 2013

which the assessor selects on the basis of comments made by the claimant; the computer is programmed to use these to generate sentences and prompt or guide further questioning and selections on the part of the assessor. The system has been widely criticised for being inflexible and for contributing to inaccuracies.

“Tickbox assessments that ignore the complexities of real people.”

3.1.2 Inadequate training of assessors

Over 70% of Atos assessors are nurses or physiotherapists. All assessors must have had at least “three years broad-based clinical post-registration experience.”²⁰ Assessors are given a minimum of 26 days training, depending on their qualification.

Professor Harrington has described the training as having impressive scope and depth; however Dr Margaret McCartney, in the British Medical Journal, questioned whether “a relatively short training course thereafter [is] enough to ensure the assessments are medically accurate and fair?”²¹

The Royal College of Nurses was sufficiently concerned that it “refused to accredit the training of Atos nurse assessors” in 2009.²²

“The worst part of the WCA for me is the Atos staff who just don't understand the illness described to them and make no effort to understand its impact.”

3.1.3 Inaccuracies on assessment forms

Serious inaccuracies were reported in 16 of 37 ESA claims (43%) analysed by Citizens Advice between summer 2010 and 2011, with a further 10 (27%) having a medium level of inaccuracy.²³

A survey in August 2012 found that a strong majority – 85% - of welfare benefits advisers considered that Atos report accuracy had *not* improved.²⁴ Moreover, 83% of decisions overturned at appeal are cases that were originally awarded 6 or fewer points – leading Citizens Advice to conclude that “something was seriously wrong with the assessment.”²⁵

“Assessment Reports: Numerous basic inaccuracies, too many assumptions made and conclusions reached without regard to reports by Consultant & GP.”

3.2 Inadequate understanding of medical conditions and of individual claimants

²⁰ Grayling, Hansard, 11 Oct 2011 : Column 357W

<http://www.publications.parliament.uk/pa/cm201011/cmhansrd/cm111011/text/111011w0002.htm#11101197001019>

²¹ McCartney, 2011

²² Royal College of Nurses, 2010

²³ CAB, 2012

²⁴ Disability Benefits Consortium, 2012

²⁵ CAB, 2012

Dr Margaret McCartney wrote in the British Medical Journal to question the ethics of allowing those without specialist knowledge to carry out assessments.²⁶ The Disability Benefits Consortium reported that “assessors’ knowledge and understanding of conditions, particularly mental health conditions, continues to be poor.”²⁷

A survey of ESA claimants by the same group found that 66% felt the assessor did not understand their impairment or health condition.²⁸

“Terrified that assessors won't understand a fluctuating condition – just because one day is manageable doesn't mean the pain won't be making me vomit the next day.”

3.3 GP and other doctors’ evidence is ignored

Atos is expected to request evidence from a claimant’s doctor when the claimant is likely to be placed in the Support Group. For the year up to October 2012, Atos requested such evidence (as an ESA113 form) in 27.2% of all ESA referrals; 23.8% of these were not returned.

The House of Commons overturned a recommendation by the House of Lords that supporting evidence be sought in all ESA cases. Only 19% of the respondents to the Disability Benefits Consortium survey felt the assessor took into account the medical evidence that was provided.²⁹

“Worst thing about ESA is the fact that my doctor knows the extent of the struggle I go through daily, as he sees me at least once a month to discuss various things to do with mental and physical health, but they talk to me for 30 or 45 minutes a year and go, “NOPE, SHE'S FIT FOR WORK BECAUSE SHE CAN WALK INTO THE EXAMINATION ROOM USING HER WALKING STICK.” Pardon my language, but WHAT A LOAD OF BULLSHIT.”

3.4 Problems with decision makers

In his first independent Review, Professor Harrington said that “Decision Makers do not in practice make decisions, but instead they typically ‘rubber stamp’ the advice provided through the Atos assessment.”³⁰ Since then there has been a small increase in the number of decisions that disagree with the Atos assessor’s recommendation, suggesting a partial decrease in ‘rubber-stamping,’ although the total number remains small. The small number of people commenting on the role of *decision makers* specifically shows how much of the assessment process is still attributed to Atos assessors.

“Worst is the feeling that my doctors could be invalidated by a clerk, at almost any time, and all long-term health management made unstable by knowing this.”

²⁶ McCartney, 2011

²⁷ Disability Benefits Consortium, 2011

²⁸ Disability Benefits Consortium, 2012

²⁹ Disability Benefits Consortium, *ibid.*

³⁰ Harrington, 2010

3.5 Going to appeal is almost a necessity for accurate outcomes

Many of the DOABS consultation responses refer to an appeal as an all-but inevitable part of the process. The stress of an appeal is as much a part of the overall stress of ESA as is the stress of the original assessment; the cycle between reassessments includes reconsiderations and appeals. When 60% of the appeals that are found in favour of the claimant originally had 0 (zero) points, this not a system where appeal is used for marginal cases. It is a system where appeal is routinely used for people who are easily too ill to work.

“Worst thing about ESA is the number of people that get the benefit refused only to win on appeal. This has to be proof that the test is severely flawed.”

3.6 Forms are difficult to complete

The 21-page ESA form contains 18 questions about a variety of activities and functions. It often takes several sessions to complete. Despite this length, it is often felt that the form does not ask relevant questions regarding the individual’s health and ability to work. Most claimants find the form difficult to complete, and it can be confusing and repetitive.³¹

“The form. It's endless. And full of traps. You get 1 month to complete it- it takes my fit and healthy husband (I've no hope of doing it) all his spare evenings/weekends and even work time to fill it in to make sure every detail is there. Terrified to leave out something they may pounce on.”

3.7 Starting a claim to receiving an outcome takes too long

Receiving an ESA decision can be expected to take at least 5 months: 4 weeks to return the questionnaire, 13 weeks waiting for the Atos medical and several weeks waiting for a decision. However, Atos and the DWP acknowledge that there are backlogs, requiring Atos to recruit more assessors and hold assessments in the evenings and at weekends.³² In February 2012, 3,122 claimants attended a centre for an assessment, but were unable to have one for reasons that are attributable to Atos.³³

³¹ Disability Benefits Consortium 2012

³² E.g. Grayling, Hansard, 1 Mar 2012 : Column 425W

<http://www.publications.parliament.uk/pa/cm201212/cmhansrd/cm120301/text/120301w0001.htm#12030153000149>

³³ Grayling, Hansard, 12 Mar 2012 : Column 81W

<http://www.publications.parliament.uk/pa/cm201212/cmhansrd/cm120312/text/120312w0003.htm#12031240001145>

“During February 2012 there were 5,353 claimants who had been scheduled to attend a work capability assessment (WCA) for employment and support allowance and, although they attended the Medical Assessment Centre, the WCA could not be conducted by Atos Healthcare.

Of this number 2,231 were for reasons which it has been contractually agreed to be outside the control of Atos Healthcare, these reasons are: being unfit on arrival to be assessed; arrived late (over 10 minutes); nurse being unable to continue with assessment; inappropriate for HCP to see; accommodation problems; unable to be seen for health and safety reasons; no prior notification of special needs; arrived on time but not prepared to wait for up to 30 minutes.” (Grayling, Hansard, 12 March 2012, Column 80W,

<http://www.publications.parliament.uk/pa/cm201212/cmhansrd/cm120312/text/120312w0003.htm>)

“The sheer length of time it takes to apply, and the lengthy appeal/tribunal process.”

4 THE ASSESSMENT DOESN'T WORK

4.1 ESA is not fit for purpose

There are a variety of reasons to believe that ESA does not work, including those cited in Chapter 1: ‘What’s Wrong With ESA?’. In addition to these concerns, many respondents explicitly stated that, in their view, ESA does not work or is not fit for purpose.

“Worst thing? That the design of the WCA is so bad that it can't even fulfil its function - to correctly assess someone's ability to work.”

“The fact that the ESA forms avoid asking about things you can score points on –it’s one of many things that leave me feeling like they are deliberately trying to make it as hard as possible for you to pass even if you qualify; its deceitful and underhanded.”

4.2 Many people are placed in the wrong group or incorrectly found fit for work

4.2.1 Incorrectly placed in the Work Related Activity Group

The reasoning behind the Work Related Activity Group (WRAG) is that people should not be ‘abandoned’ on sickness benefits when they may be able to work in the future. However, many people in the WRAG report that they struggle to meet the work-related activity requirements. For those who can manage, the offered support is often deemed of little practical use – the DBC survey above found that almost 50% of respondents had received no support, whilst others had had one interview and then very little else.³⁴

“The WRAG is unfair parking space for those not fitting JSA OR SG- it should only be used for those where health recovery is possible or only thing preventing work is support. Pushing meetings/workfare/time limits where health is never going improve is [the] worst thing.”

4.2.2 Incorrectly found Fit For Work

The government does not regularly track those who are found fit for work, and thus misses a lot of data on the accuracy of those decisions. A small study found that only 28% of those found fit for work are in work 12-18 months later – in comparison, three quarters of JSA claimants are in work 6 months after starting their claim.³⁵

The high percentage of appeals overturned – as already seen, various figures between 70% and 100% are reported when a representative is involved – are also indicative of how many fit for work decisions are incorrect.

³⁴ Disability Benefits Consortium, 2012

³⁵ Barnes, et al., 2011

“The worst has to be when they sent me for a medical, I was that ill from the stress of it I suffered extreme psychosis on the day itself yet was still deemed fit for work. The shrink got involved and said no we appeal, waiting 9 months for appeal date, that was horrific felt like a criminal. I dread another medical or meeting or assessment.”

5 Poverty

Responses to the survey by the Disability Benefits Consortium showed that advisers overwhelmingly believe that “increasing numbers of people are being left without adequate support by the welfare system.”³⁶ This is exacerbated by lack of security over future retention of benefits.

Poverty does not just mean financial lack, but also covers social issues. Many people receiving ESA find themselves dependent on others or unable to adequately care for those who are dependent on them.

“Having to rely on my 80 year old mum to send me money in the post every week, as reduced rate of ESA didn't even cover half of what was needed for bills, mortgage, Zilch left for food or petrol.”

“Fear of being found fit to work when I can't work at all, and losing custody of my son to his abusive father as a result of all the other consequences that would ensue.”

6 TIME LIMIT

Since 2012, ESA claimants placed in the WRAG and eligible for contributory ESA have had these higher payments limited to a maximum of 52 weeks. Prior to the implementation of this measure, the government made it clear that significant numbers of claimants would be in a position to lose out under the change: “It is estimated that in steady state, without time-limiting, around 77% of contributory ESA claimants in the Work Related Activity Group or Assessment Phase would have a duration of 12 months or more.”³⁷

When Professor Paul Gregg originally designed ESA, he assumed and advised that claimants generally needed *at least* 2 years to recover to the point of considering work. Nevertheless, ministers have made it clear that the idea of a time limit was not based on whether or not people had recovered, or whether they had found work, but predominantly on cost grounds: “ESA has always been intended to be a temporary benefit for those in the Work Related Activity Group. It is important that we rebalance the benefit system so that it is fair to recipients as well as being affordable to the taxpayer.”³⁸

³⁶ Disability Benefits Consortium, 2012

³⁷ Grayling, Hansard, 3 May 2011 : Column 723W

<http://www.publications.parliament.uk/pa/cm201011/cmhansrd/cm110503/text/110503w0005.htm#1105041001309>

³⁸ Miller, Hansard, 31 Jan 2011: Column 586W

<http://www.publications.parliament.uk/pa/cm201011/cmhansrd/cm110131/text/110131w0004.htm#11013139000675>

The government have argued that those subjected to the time limit would subsequently either qualify for income-based ESA or have “other means of support”, but in reality, the means test for the latter is set at a maximum combined income of just £7,500 per year. As a result, many families lose out on their ESA payments altogether upon expiry of the time limit, despite there often being no change in a claimant’s condition or support needs.

“The 1 year limit. I'm not miraculously cured of my non-curable disease just because my partner is lucky enough to have a job.”

Implementation of First-year Harrington Review Recommendations

Summary

Whilst the government claims it has 'accepted' all of the 25 recommendations made in Professor Harrington's initial Review, this does not mean that they have been incorporated into the ESA assessment process. Improvements to the ESA process therefore cannot be assumed based on the recommendations. It is necessary to examine what has been done regarding each recommendation.

The results show that success has been much more limited than the government's 'acceptance' would suggest.

Of 25 recommendations, almost two-thirds have not achieved success. Three were not implemented at all; five were implemented with limited success; and eight were not fully implemented, which consequently also means a limited success.

This lack of success means the recommendations have not brought about the improvement to the ESA system that they could have, had the government fully accepted and implemented the recommendations.

Overview of implementation

Three recommendations were not implemented.

- Two of these were because they were beyond the Review's remit, being related to the Tribunal system.
- The third was that Decision Makers should be able to contact a claimant's chosen healthcare professional "to provide a view on the accuracy of the report." This has not been done and no explanation, reason or justification has been given for this.

Nine recommendations were fully and successfully implemented.

- Include a personal justification in the ESA50 form;
- Include a personalised summary from the Atos assessor;
- Increase the role of the Decision Maker;
- Make better use of the reconsideration process;
- Find out what happens to claimants after a decision has been made;
- Examine consistency between Atos assessors of different professions;
- Monitor the implementation of recommendations;
- Ask for recommendations on the metal, intellectual and cognitive descriptors (ongoing); and
- Examine the descriptors, particularly for fluctuating conditions and possibly for generalised pain (ongoing)

Five recommendations were fully implemented but with limited success.

- Review the ESA50 “to ensure it is the most effective tool for capturing relevant information about the claimant”;
- Atos should publish a charter of claimant rights and responsibilities, and consider publishing online the guidance that they provide for healthcare professionals;
- There should be better communication between Decision Makers and Atos healthcare professionals regarding borderline cases;
- Decision Makers should “receive training so that they can give appropriate weight to additional evidence”; and
- Examine the computer system used by Atos.

Eight recommendations were not fully implemented.

- Jobcentre Plus should manage and support the claimant during the course of their benefit claim and identify their chosen healthcare adviser;
- Written communications should be “clearer, less threatening, contain less jargon and fully explain the process”;
- Mental, intellectual and cognitive champions should be provided in each medical assessment centre. “These champions should spread best practice amongst Atos healthcare professionals in mental, intellectual and cognitive disabilities”;
- Carry out a pilot of audio recordings to see if this would be helpful;
- Research the use of “more ‘real world’ or work-focused elements” in the assessment;
- Send a copy of the Atos personalised summary to the claimant, and allow the claimant to “discuss any inaccuracies with a Decision Maker”;
- Feedback from the First-tier Tribunal should be routinely shared with Jobcentre Plus staff and Atos healthcare professionals, while “as part of their professional development, Jobcentre Plus Decision Makers should be encouraged to regularly attend Tribunals”; and
- Examine what happens to people who are found fit for work but are unable to claim Jobseekers Allowance.

Please refer to Appendix C for a much fuller analysis on the progress of each of the 25 first-year Harrington recommendations.

International Evidence

The UK is not the only country to attempt radical reform of out of work sickness and disability provision with limited success. Nevertheless, other countries have adapted to familiar setbacks in different ways: some by approaching the challenges of service provision in a more holistic way, others by beginning the process of reversing and improving earlier reforms.

We now know much more about what works and what fails. The evidence base has increased dramatically in the 8 years since the UK government first designed ESA and it is vital that this evidence base now informs further reforms.

This section gives a brief overview of the experiences and lessons of welfare reform learnt elsewhere.

Australia

Australia has had a system similar to the UK's Work Programme since 1998. Providers were selected through a tendering process, and funding was based on completing services and achieving outcomes.

Jobseekers are streamed into one of four categories depending on their assessed distance from the labour market, and payments are based on the outcome of this process.

This funding strategy created the same problems with "cherry picking" and "parking" that the UK government has seen with its Work Programme. The lack of reward of interim milestones, including soft skills, and the low rate of remuneration means that companies often have to select those jobseekers who are easiest to place in order to remain financially viable.

Ten years on, problems in Australia included a lack of flexibility, poor targeting of resources to the most disadvantaged, and high levels of administration. A new generation of services was introduced on 1 July 2009, with a new contract for disabled people introduced on 1 March 2010. However these have not alleviated the problems.

In particular it has been noted that the services assume a linear return to work, where "barriers to employment are progressively and permanently overcome."³⁹ This is inappropriate for disabled people, where a problem may never go away; for example,

"Staff with experience of job seekers with mental health issues talk about "the 12 week cycle" where clients gain employment, but around 12 weeks experience an episode where more intensive support is needed before the client's situation stabilizes once again..."

³⁹ Nevile and Lohmann, 2011

Staff also noted the difficulties job seekers with an intellectual disability have in separating their work and non-work lives.

'If something bad happens at home, something bad is going to happen at work, so you have to keep over the top of all that and there is no funding for that...If we don't pay attention to home issues, they won't be at work for much longer because they will say [something inappropriate] or do [something inappropriate] or just stop going (Team Leader, specialist ID agency).'"⁴⁰

The emphasis on work is heavily criticised. Whilst Australia has a Social Inclusion Agenda and a Disability Services Standard, providers nevertheless found a conflict between meeting these outcomes and meeting the job outcomes, which were the ones being paid for. Staff found they were pressured to find work for people who were not job ready, or were unable to provide support that they wished to provide, because of financial constraints.

The assessment for Australia's ESA equivalent has also been criticised:

*"DES agencies have been placed under further financial pressure by inappropriate job capacity assessments and funding level decisions. The main cause of inappropriate assessments is the mismatch between disability and the professional qualifications of the Job Capacity Assessor. Staff pointed out that it was unrealistic to expect a registered nurse or an occupational therapist to be able to make an informed assessment of a client with mental health issues, even setting aside the difficulties involved in trying to establish a level of rapport in a brief initial meeting such that the job seeker feels sufficiently comfortable to reveal information about their disability and their work capacity. Job seekers also found it strange that "you go and see someone for an hour that you have never met before and they are meant to make a capacity assessment."*⁴¹

Instead it was recommended that,

*"Job capacity assessments should be treated as a dynamic process with information collected over three months or so. Job Capacity Assessors [i.e. Decision Makers] in Centrelink [i.e. JobCentres] should make the initial assessment based on available information in the job seeker's file. No face-to-face interview is required. Employment agencies then provide further information gathered from interaction with the job seeker over the next three months. At the end of the three month period, the Job Capacity Assessor reviews all information, paying particular attention to information provided by the employment agency, and makes a final decision as to current job capacity."*⁴²

Recommendations:

- Upfront fees to increase provider's capacity to assist claimant with intensive needs.

⁴⁰ Nevile and Lohmann, *ibid.*

⁴¹ Nevile and Lohmann, *ibid.*

⁴² Nevile and Lohmann, *ibid.*

- Pay fees for intermediate milestone and soft-skill outcomes.
- Allow employment outcomes to cover several jobs – although being able to sustain one job is beneficial, the ability to ‘taste and see’ can be very valuable.
- Allow the claimant to choose their provider. Providers who are successful at placing claimants in jobs quickly will thereby gain a good reputation.
- Allow the caseworker and claimant to set the support programme, including meeting less often with claimants who are doing well and do not need frequent meetings.
- Assess people correctly in the first place, via a three-month process of interaction by the caseworker with the claimant and a decision by an independent DM based on the caseworker’s report and other supporting evidence.
- Do not review cases annually, as the caseworker can do this during the process of working with the claimant. A claim can be reviewed as and when there are significant changes in the claimant’s circumstances.

Personal Support Programme.⁴³

The Personal Support Programme (PSP) was introduced in Australia on the basis that “the most disadvantaged job seekers are not well served by mainstream welfare-to-work models based on rapid labour market attachment and minimum cost interventions”; that these people are “less able to meet more onerous welfare-to-work requirements and are significantly more likely to be sanctioned”; and that “the more barriers an individual faces the lower the likelihood they will exit welfare-to-work and then stay in work.”⁴⁴

Consequently the PSP was set up to address personal barriers without any work requirements. Engagement with the PSP was satisfactory for meeting benefit conditions. PSP was aimed at people with barriers that “include mental health problems, homelessness, family breakdown, substance abuse, chronic health problems, and social isolation.” Despite these barriers, when surveyed “the vast majority of clients reported a desire to participate in either employment or further education and training and a large proportion (58%) have engaged in some form of employment over the past two years; however, the majority of this is casual work.”⁴⁵

Soft skills for which payment was given included:

- Improved self-confidence/self-esteem
- Positive attitude to achieve goals
- Increased ability to control anger
- Effective coping strategies
- Improved interpersonal skills
- Ability to set personal goals
- Better able to make decisions
- Improved personal care
- Increased feelings of self-worth

⁴³ See Perkins, 2005 and DSS, 2012

⁴⁴ Perkins & Nelms, 2004; Perkins, *ibid.*

⁴⁵ Perkins and Nelms, *ibid.*

- Increased ability to cope in stressful situations
- Improved family relationships (FaCS 2002).

Caseworkers in PSP were “almost unanimous” that it is “an effective and crucial programme.”

Unfortunately, PSP suffered from:

- Inadequate resources, in terms of people, money and information;
- Lack of ongoing staff training specific to this client group;
- Lack of integrated employment or community participation activities for those clients who have the capacity to undertake them;
- Lack of ongoing barrier-specific post-employment personal support;
- Restriction to two years meant some claimants regressed once PSP had ended – however some case managers felt that the limit prompted claimants to “start thinking seriously about the changes they wanted to achieve.”

Recommendations:

- The UK should provide holistic and non-work support to people with health barriers, but this must not exclude vocational work where this would be appropriate;
- The UK needs to direct sufficient resources to helping these people;
- Caseworkers must be adequately trained;
- Caseworkers must continue to work with claimants once they are in employment.

Netherlands⁴⁶

Policymakers in industrialized countries frequently attempt to contain the costs of sick leave and disability schemes by limiting access to include medically proven cases only. However, a person’s incapacity to work cannot be fully deduced by referring to his or her medical condition.

The key question here is whether use of more restrictive eligibility criteria that focus on medical evidence actually reduces the number of benefit recipients and makes access to employee benefit arrangements fairer. Meershoek’s ethnographic study shows that physicians working in Dutch illness certification practices use alternative methods to restrict access to sick leave programmes.

Doctors do not control their clients in a restrictive sense of the word. Rather, they exercise control over their clients by inciting them to internalize social norms about being active and responsible. While we do not claim that this is a good policy per se, we do contend that this broad control style may have some advantages over and above more restrictive control mechanisms. Elaborating on policy that supports this alternative notion of control, therefore, seems worthwhile.

⁴⁶ See Meershoek, 2012

What happens?⁴⁷

An employee who goes on sick leave is assessed by a physician. The physician is employed by an arbodienst, a private organisation responsible for advising employers on the legitimacy of the sick leave and providing social-medical coaching to the employee. Most arbodiensten are specialised in a particular sector.

The physician and employee meet up regularly, depending on how often is required. The employee is encouraged to take the initiative and act as a responsible person rather than a person under examination. There is a strong emphasis on trust and a good relationship; sanctioning is avoided as much as possible as it is seen as detrimental.

In the Netherlands, Vocation Rehabilitation Professionals (VRPs) work at specialized vocational rehabilitation services, which can be either for-profit or non-profit organizations.

According to the Dutch legislation, the employee and the employer are responsible for the work reintegration of sick-listed employees during the first two years of sick leave. VRP provide support to the employer in the management of return to work (RTW) in case of sickness absence. Employers are free to choose the vocational rehabilitation service that best fits the specific needs of their employees.

The services offer different work rehabilitation programs according to the specific needs of the sick-listed employee, including a VRP that coordinates the RTW activities such as workplace assessment, worker training, case management, outplacement, career counselling, referral to specific training and training in job applications.

Recommendations:

- Recognise that medical diagnosis alone is not sufficient;
- Early intervention where someone starts Statutory Sick Pay (SSP) or claims ESA (in the Netherlands it is between 2 days and 4 weeks, depending on the arbodienst agreement with the employer);
- Encourage initiative on part of claimant so claimant 'owns' the support plan; if claimant cannot do this then the assumption should be that the claimant lacks the appropriate skills, not that the claimant is faking illness;
- Permit phased return to work;
- Give more freedom to claimants who demonstrate responsibility;
- "Commitment on the part of the claimants is the best guarantee for a successful reintegration in the long term";
- Avoid confrontations and sanctions as far as possible as they are counter-productive.

Scandinavia

⁴⁷ See: Dekkers-Sánchez et al., 2013

Iceland⁴⁸

The instrument works in a systematic way to motivate and activate the individual by stressing what they can do, and by minimizing function loss and increasing adaption with early intervention and vocational rehabilitation at the same time.

The method itself is a continuous process of information gathering in a structured way, where the aim of the whole assessment process is to increase the individual's work ability by exploring and trying all options from a comprehensive view.

The information that is gathered in this process is valuable when it comes to choosing what options are available in vocational rehabilitation and when making decisions regarding eligibility to disability benefit.

Norway

The Norwegian Labour and Welfare Service (NAV) looks at work ability in terms of an individual's ability to obtain or retain employment. The working capacity of the person can change over time due to health, qualifications or the situation in the labour market. Therefore resources and limitations are assessed in relation to what the workplace and daily life demands.

At the same time, opportunities that exist are considered. The goal is to make use of the individual's opportunities in the workplace as well as in daily life. A plan with various measures that help to reach this goal is made.⁴⁹

Denmark

Assessment on work disability underwent profound changes in Denmark in January 2003. The new method is called Arbejdsevneметоден, where the aim is to clarify an individual's abilities in connection to the labour market.

The primary goal is also to investigate additional requirements and the possibility of improving the individual's capacity to work. The decision to award disability benefits depends on the functional ability of the claimant in relation to the labour market, not the medical diagnosis in itself.⁵⁰

A consultant uses the Arbejdsevneметоден to describe a citizen's resources by completing the Resourceprofilen (Resource Profile). The Resource Profile is a tool where the consultant can describe the citizen's resources based on 12 factors.⁵¹ Those twelve factors are

- Former education;
- Work experience;

⁴⁸ See: Konráðsdóttir, 2011.

⁴⁹ Norwegian Labour and Welfare Service b, 2010

⁵⁰ Boer et al, 2004

⁵¹ Boer et al, ibid.

- Interests;
- Social competences;
- Abilities to reorient;
- Ability to learn;
- Wishes for the future;
- Own expectations of future performance;
- Level of work identity;
- Housing conditions/ economic conditions;
- Social network; and
- Health.

All these elements are regarded important in the individual's life and all of them have relevance to the demands of the labour market.⁵²

Sweden

SASSAM is a structured method for investigating cases of illness and coordinating them into rehabilitation. At the same time SASSAM offers a systematic approach and serves as a common working instrument.⁵³

It is a structured methodology and is based on knowledge in medicine, behavioural sciences, psychology and sociology with the purpose to support a dialogue with the individual. SASSAM's main purpose is to streamline, professionalize and improve the quality of rehabilitation work.

The method looks at resources and barriers in a holistic way and requires participation by the individual. The aim is to reach a common understanding of the barriers and resources, to value individual resources and define how obstacles can be overcome when rehabilitation is planned.⁵⁴

Recommendations

- Definition of ability to work is based on more than health, as qualifications, home life etc. will have an impact;
- Information is gathered over a period of time, not one interview;
- Intensive support and rehabilitation needs to be offered.

⁵² Socialministeret, 2001

⁵³ Forsäkringskassan, 2009.

⁵⁴ Forsäkringskassan, ibid.

Alternative to ESA

Evidence for assessment and qualifying criteria.

Professor Harrington, then leader of the Independent Reviews of ESA, criticised those sceptical of the current structure of ESA for not detailing what should be in its place. Here we aim to do just that.

There is now substantial international evidence to show what does and does not work when assessing and supporting disabled people. Unsurprisingly, ESA and the Work Programme fails in many areas, whether on providing valid assessments, or providing adequate and suitable support once the assessment has been completed.

The following section provides evidence in support of alternative methods through which the assessment process could be conducted.

Early Intervention

One of the most important stages of any assessment process is to ensure early intervention. Repeated studies show that the earlier an intervention occurs the less support is needed to return to work, and the quicker and more sustainable that return is.⁵⁵

In the Netherlands, assessment and support occur concurrently and start between two days and four weeks after starting sick leave, depending on the exact arrangements between the employer and the Arbodiensten who provide the assessment and support.⁵⁶

With ESA this does not occur; there is a minimum 13 weeks before assessment and with high backlogs many people wait much longer. When someone has already gone through 28 weeks of Statutory Sick Pay and then, after receiving ESA, has another wait before meeting an adviser, there can be 9-12 months delay.

There is therefore considerable scope to bring in earlier interventions. Where a person becomes ill or disabled whilst in work, assistance should start within a few weeks of claiming Statutory Sick Pay: i.e. even before a claim for Employment and Support Allowance is made. Increasing the support and interventions available during SSP may help to reduce the proportion who continue on to ESA. If the person is not in work, then assistance should start within a few weeks of entering a claim for ESA.

Waiting times before a claimant can access treatment and the time that treatment takes can act as barriers to returning to work, as the claimant often wants or needs to wait for treatment to be completed before returning.⁵⁷

⁵⁵ Franche, et al., 2005; Carroll, et al., 2010; Hoefsmit, et al., 2012

⁵⁶ Meershoek, 2012

⁵⁷ Wright, 1997; Anema, et al., 2002

Focus group research among patients on long term sickness leave found that inefficient and inadequate healthcare increased their anxiety and uncertainty about returning to work. One subject felt:

*“They expect you to pull yourself out of the swamp”.*⁵⁸

This can result in GPs recommending longer periods of sick leave.⁵⁹ Combined with the increased effectiveness of early intervention, it is clearly an important part of facilitating a return or move into work that the health service provides treatment sooner rather than later.⁶⁰

Role of GPs

In the UK there have been repeated calls to put GPs in the role of assessor and decision maker for sickness benefits. However, this is not a role that GPs either want or are qualified for. GPs more usually act as advocates for their patients, and to act as a gatekeeper would conflict with this role.⁶¹

GPs also express concerns over their knowledge of the requirements of a particular job or jobs generally, and over their knowledge of the functional limitations that their patient experiences.⁶² A low continuity of care and few home visits further reduce a GP’s knowledge of their patient and his or her capabilities.

This does not mean that the GP does not have an important role in the assessment and support process. On the contrary, the input of GPs and other appropriate healthcare professionals is vital to the accuracy of assessment.

The British Medical Association said:

*“The claimant’s GP also has a specific role in the process, to provide a factual report based on information contained within the patient’s medical record.”*⁶³

Similarly, Oxford Welfare Rights advised the Work and Pensions Committee that:

*“GPs and other healthcare professionals are likely to be best placed to provide detailed evidence regarding a claimant’s capabilities.”*⁶⁴

The input of a medical professional to confirm or refute a claimant’s diagnoses, treatment and likely effects of these factors on ability to work is vital. GP input (or that of another

⁵⁸ Dekkers-Sanchez et al., 2010

⁵⁹ Engblom, et al., 2011

⁶⁰ Wright, 1997; Kuoppola & Lamminpää, 2008

⁶¹ Hussey, et al., 2003; Wynne-Jones, et al., 2010

⁶² Engblom, et al., 2011

⁶³ See Harrington, 2013

⁶⁴ Oxford Welfare Rights, ‘Submission to Work and Pensions Select Committee’:

<http://www.publications.parliament.uk/pa/cm201012/cmselect/cmworpen/writev/1015/esa19.htm>

suitably qualified and appropriate health care professional) should accompany the claim for a sickness benefit, possibly as part of the same document and an ESA113 form or similar should be sent out early in every claim with the expectation that they will be returned.

Currently in the UK there is a fast-track mechanism for people who are terminally ill. It may be worth extending this to those who clearly are unable to work due to gross impairment, sickness, or risk (as currently defined by regulations 29 and 35), potentially via a GP sign-off.⁶⁵

Automatic entitlements

Most countries acknowledge that there are some people who cannot or should not work at all. Often this is done by assessing the likely duration of the disability, and placing anyone who is likely to be disabled for two or more years onto a disability pension or equivalent. However this may not be appropriate, as lifelong or likely long-term disability is not necessarily entirely work-disabling. For example, a person with a learning difficulty who can work in supported employment may not wish to be placed on a benefit where a life without work is assumed. Conversely, a person presenting with difficulties arising from a degenerative condition will be moving away from the employment market.

"I clearly don't fall within the Support Group criteria, so according to DWP that means I should be doing 'work-related activity' to prepare me for my eventual return to the workforce, but in 25 years of disability the trend has been progressive, and my consultant has said recently that he absolutely can't see a way back into the workforce for me. It is very common for a disabled person to only meet the WRAG criteria, yet have no possibility of returning to work in the near term."

Nonetheless, it is not reasonable for some to engage in any kind of work/work related activity unless they choose to do so. A more holistic assessment, based on a series of meetings/interactions should simply look at the barriers a person faces and seek to overcome them. If the claimant and assessor agree that no form of engagement is appropriate, then that opinion must be adequate to ensure long term, unconditional support with any future engagement on a purely voluntary basis. We recommend a small extra payment for claimants where this is the outcome.

Similarly, we recommend that claimants working towards overcoming barriers with a plan agreed jointly with their case worker also receive the extra payment as a form of incentive.

Full assessment

Another important factor in accurate decision making is access to a full evaluation. This means extending the assessment beyond the medical-only focus of ESA.

⁶⁵ See <http://kittysjones.wordpress.com/2013/04/21/1560/>

The most effective interventions are those that actively consider non-medical aspects of an individual's ability to work and that deliberately set out to assess and then work on these factors alongside the medical issues.⁶⁶

A Scandinavian study found that having a combined work-load (i.e. domestic, caring or parenting roles as well as work) perpetuated long term sick leave. Age was another non-medical barrier cited:

*"Who wants to employ a 57-year-old man with sight problems and degenerative disease?", "60 years old, that's a barrier".*⁶⁷

More information makes it easier to make an accurate assessment and then provide appropriate support.⁶⁸

It is known that disabled people with higher educational qualifications are less disadvantaged in the job market compared to disabled people with lower educational qualifications. This might be through a combination of more transferable skills, higher self-efficacy and more contacts within the job market. Additionally, higher-level work is more likely to be desk-based, which can be important for people with fatigue or pain-related conditions.

Some people also face significant private barriers to work that may need to be addressed first, such as homelessness, substance abuse or recent release from prison. As many of these people often have health conditions they may be likely to qualify for ESA, so it is important that the ESA assessment and support process recognises the kinds of private issues that can exist on top of health conditions. Australia used to have a Personal Support Programme for such people, to work on life issues before trying to address any work issues.⁶⁹ Another study suggested a similar principle, quoting a vocational rehabilitation professional,

*"If the person has serious private problems, then you should first help him to solve or alleviate these issues. Due to the great impact of these private issues on the lives of employees, it is urgent to tackle these barriers first; otherwise work rehabilitation will not succeed."*⁷⁰

The criteria for access to sickness benefit should therefore be formulated in such a way as to take into account the non-medical factors that interact with the medical factors.

The Work Capability Assessment for ESA consists of a series of activities, for which the ability to carry out the activity to varying levels results in various points being awarded. For example, whether the claimant can: "move between one seated position and another

⁶⁶ Dekkers-Sanchez, et al., 2013

⁶⁷ Dekkers-Sanchez, 2010

⁶⁸ Dekkers-Sanchez, et al., 2011; Dekkers-Sanchez, et al., 2013

⁶⁹ Nevile & Lohmann, 2011

⁷⁰ Dekkers-Sanchez, et al., 2011

seated position which are located next to one another without receiving physical assistance from another person”; or “pick up and move a 0.5 litre carton full of liquid”.⁷¹

This is an inappropriate way to assess a person for sickness benefit, because it very clearly ignores the consequence of other factors and does not at any point consider what job the claimant is supposed to be capable of doing. Additionally, in isolation the physical skills tested are below those needed to gain even entry level employment.

“If we must have a test that measures function to assess ability to work then it must be based in the real world. I haven't seen any jobs that are entirely based on me going into work, picking up a box and “Thanks very much, that's all for today.”

“There is no cure for my Seronegative Arthritis/ Lupus, Fibromyalgia, or my son's autism. We are never going to be “cured”. And there is no 10-minute test to see whether or not I can pick up a coin or press a button which will determine if either of us is fit for work as there's precious few jobs out there which require us to only pick up coins or press a button once an hour.”

International evidence suggests that assessment should explicitly focus on what work or job role the claimant is supposed to be capable of doing, what barriers exist and how these can be overcome. Thinking about assessment in this way leads naturally to a list of criteria that are based on work restrictions and necessary support.

Process of Assessment

A full assessment necessarily requires that the assessment be carried out accurately. A one-off meeting with an external assessor who uses an adversarial approach is likely to be inappropriate. The following testimony shows how information supplied by claimants seeking a constructive dialogue with assessors can be used against them with devastating consequences:

“I was doing all right. I was seeing some recovery and doing a small amount of voluntary work, but because I was naive enough to tell the nice ATOS lady about it they removed my benefit. This made me worse and I am now permanently under the care of the CMHT with the resources that uses. My recovery has been put on hold while I appeal that decision and our lives have been put on hold until we know the result of that.”

Advisers report that it can take several meetings to obtain all the information surrounding a claimant's ability to work: in a one-off assessment there is not time to build up rapport and trust, and vital information is more likely to be withheld.⁷²

⁷¹ See Employment and Support Allowance Regulations 2013, Schedule 2:
<http://www.legislation.gov.uk/uksi/2013/379/schedule/2/made>

⁷² Nevile & Lohmann, 2011

The Work Capability Assessment has been criticised as being a snapshot: any observation made by the assessor during the brief interview is necessarily a one-off that may not represent overall capability, particularly where repetition and reliability is an issue.

We recommend that assessments should therefore occur over several meetings with a consistent caseworker to reduce the snapshot affect and to increase the amount of accurate evidence collected. This has been recommended in Australia,⁷³ and is already used in the Netherlands⁷⁴ and Canada.

An adversarial style means that the assessor is looking to challenge the claimant's position and assumes that the claimant is able to defend themselves. In reality, claimants often do not know what information is needed for their claim and find it difficult to express their needs in a stressful environment. This is particularly true for claimants with mental health difficulties:

"I felt as if I was on trial and having to prove myself to people who wanted to trip me up and find reason to deny me support. It's soul destroying to have to prove how mentally unstable you are to a faceless stranger reading about you in an office somewhere, or the assessor for that matter. Usually mental health professionals build up a relationship with you before they probe your suicidal thoughts and so forth. They don't ask on first meeting how often you harm yourself or if you've tried to kill yourself. It's just callous, cruel and intrusive and potentially dangerous."

In contrast, the Tribunal services recommend an inquisitorial approach in which it is the role of the panel to elicit the necessary information.⁷⁵ This may be one reason why Tribunals obtain more oral evidence than do WCA assessors, and why so many decisions are overturned at appeal. The assessor should therefore use an inquisitorial style in which he or she actively seeks evidence and explanations for what the claimant can and can't do. The Assessor should not have been exposed to bias regarding their role, nor be under suggestion or compulsion as to an outcome.

Once the process of assessment is complete, we believe that evidence should still be submitted to an independent Decision Maker to confirm or deny the progression onto out of work sickness support. The Decision Maker should decide whether or not the person meets the criteria specified in the above subsection, Full Assessment. Having an independent Decision Maker may promote a good relationship between the claimant and their assessor/case worker, and may reduce conflict where the claimant wishes to appeal a decision.

In practice this process may remove the need for reassessments. As the caseworker and claimant work together on moving towards work, actually gaining work will be the appropriate point at which the benefit ends. There is further reason to allow this in that,

⁷³ Nevile & Lohmann, *ibid.*

⁷⁴ Meershoek, 2012

⁷⁵ Judge Hale, 2004

even where a recovery has occurred, the risk of relapse and substantial distance from the job market may still remain, and thus continue the health-related disadvantage. Where a recovery has occurred and been sustained to the extent that ESA criteria are no longer fulfilled then it may be appropriate for the caseworker to have responsibility to initiate a reassessment, including seeking evidence or expectation from the claimant's GP or other healthcare professional on the degree and permanence of recovery.

Relevant experience

As addressed in Chapter 1, 'What's Wrong with ESA', it is known that the qualification of the assessor can negatively impact the number of points awarded. A recent tribunal case ruled that the opinion of the assessing physiotherapist was not admissible as evidence of the claimant's mental health capabilities. Australia has also experienced difficulties with assessors lacking experience in the condition of the person they are assessing.⁷⁶ In the Netherlands, the physician who carries out the assessment and support process is specialised in a particular industry.⁷⁷

It is strongly recommended that the assessor have experience in the relevant disability.

Medical Advances

It is imperative that a clear record of diseases, conditions, illness and impairment is kept by the DWP. It is the role of the DWP to keep abreast of medical advances that may be reducing the barriers to employment, and it would not be an unreasonable assumption that the DWP could re-assess claimants who have possibly had treatments. Conversely, it would be unnecessary and an inappropriate additional expenditure for the DWP to re-assess those whose conditions are incurable or degenerative.

Whilst different disabilities may benefit from different approaches, still there are a number of generic factors that can, based on international academic literature, be recommended as beneficial for all.

These recommendations assume that the assessment has been carried out fully, early on and by a sufficiently experienced and knowledgeable person.

Multi-disciplinary

Multi-disciplinary interventions consistently increase the speed at which those off sick are able to return to work⁷⁸ and reduce the risk of long-term need for incapacity benefits or disability pensions.⁷⁹ Dekkers-Sanchez and her colleagues conclude that, for people on long-term sick leave:

⁷⁶ Nevile & Lohmann, 2011

⁷⁷ Meershoek, 2012

⁷⁸ Hoefsmit, et al., 2012

⁷⁹ Kuoppala & Lamminpää, 2008

“The use of combined interventions in a holistic approach involving the worker and his environment is considered the best way to address the multi-causality of work disability and could help maximize RTW outcomes.”⁸⁰

These benefits are even greater for people who have been off sick for longer or who have more complex conditions, perhaps because those who have been off sick for only a short time or have simple conditions do not need such intensive support.⁸¹

Internationally, the disciplines considered important include social care; health care such as a GP, a psychiatrist or physiotherapist as relevant, and a specialist; occupational health and vocational rehabilitation; the employer, line manager or workplace; and a caseworker to bring all the disciplines together and co-ordinate, with the claimant, a plan for moving towards and into work.⁸²

In the UK, we recommend that a caseworker should assist with access to other social security benefits such as Personal Independence Payments; co-ordinate social care and Access to Work; and liaise as necessary with the claimant’s healthcare team to co-ordinate health management with moving – where possible – towards or into work. Furthermore, as detailed below, it is vital that the UK invest properly in vocational rehabilitation.

Access to treatment

Many studies compare vocational rehabilitation to none; or multi-disciplinary rehabilitation to single-discipline. It is a common finding that decent access to medical treatment (currently there are often delays in accessing treatment and treatment may be restricted to inappropriate types) must be provided as well as what might be termed occupational or vocational interventions, not one or the other. This is particularly important for people with long-term conditions.⁸³

However in the UK, people with long-term disabilities may suffer inadequate access not only to medical care, but also to vocational rehabilitation.⁸⁴ In 2002 the UK had fewer than 2 rehabilitation medicine consultants per million people; of 12 other western European countries, the next lowest was Germany at 13 per million.

⁸⁰ Dekkers-Sanchez, et al., 2011

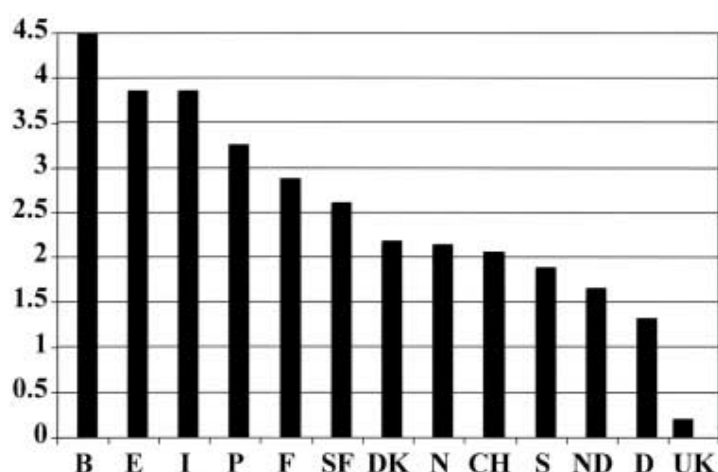
⁸¹ Poulsen, et al., 2012

⁸² Kuoppala & Lamminpää, 2008

⁸³ Kuoppala & Lamminpää, *ibid.*; BSRM, 2000

⁸⁴ BSRM, *ibid.*; Waldron, 2001

Numbers of accredited specialists in physical medicine and rehabilitation in 12 western



European countries as expressed per 100 000 of the population. UK NHS rehabilitation consultants and associate specialists are shown for comparison. The countries in order are Belgium; Spain; Italy; Portugal; France; Finland; Denmark; Norway; Switzerland; Sweden; Netherlands; Germany; United Kingdom.

Taken from Grahame (2002).

Individual placement and support

Of all back-to-work interventions, the Individual Placement and Support (IPS) model is consistently the most successful in assisting long-term disabled people into work. This effect holds across age, gender, ethnicity, education, and other characteristics such as homelessness and substance abuse⁸⁵ as well as across countries.⁸⁶

It is cost-saving compared to standard vocational rehabilitation services and is likely to be more cost-effective.⁸⁷

IPS is a well-researched intervention with proven, standardised procedures⁸⁸ and fidelity measures.⁸⁹ It is composed of:

- 1) Commitment to competitive employment, so that resources are not directed away to other methods such as sheltered employment;
- 2) No exclusion based on distance from job market;
- 3) Rapid job search, i.e. no pre-employment training;
- 4) Individualised job brokering in which employment specialists and claimants find placements according to claimant preferences, strengths and experience, and give attention to client preferences;
- 5) Indefinite duration of in-work support;
- 6) Collaboration with the claimant's medical team; and
- 7) Advice on social security and other benefits.

⁸⁵ Campbell, et al., 2011

⁸⁶ Bond, et al., 2012; Knapp, et al., 2013

⁸⁷ Knapp, et al., 2013

⁸⁸ Campbell, et al., 2011

⁸⁹ Bond, et al., 1997

Individual aspects of IPS have been shown to be beneficial on their own compared to not using them. ISP participants typically start with a small number of hours and increase over several months.⁹⁰

Returning to work before a full recovery is made can be beneficial, making a return to full-time work more likely⁹¹ and resulting in a faster return to full-time work.⁹² Finding work that interests the claimant is also beneficial.

It is vital that the claimant is actually able to perform the work they are supposed to be doing.⁹³ Sustained returns to work are more likely when support continues once a person is in employment.⁹⁴ Appropriate job placement and on-the-job support also help to achieve and maintain employment.⁹⁵

Relationships at Work.

Interventions that include the workplace are in general more effective than those that do not.⁹⁶ Such interventions can reduce subsequent sick leave⁹⁷ and speed the return to work.⁹⁸ It is therefore important that where a person is on SSP or is claiming ESA and still has a contract, the workplace is involved with plans to facilitate a return to work.

Supportive work environments make returning to work easier⁹⁹ and are reported to be a key determinant of successful integration.¹⁰⁰ A caseworker can help to promote good relationships between the employee and his or her employer or line manager, and between the employee and colleagues.

Returning to work is encouraged when the employee does not feel that the employer is pushing them too far or too fast or that the employer views them as a statistic rather than a person. Work is more sustainable when the co-workers are supportive of the person and have some appreciation of the disability.

Disability Specific.

Generic interventions aimed at all employees on sick leave, regardless of diagnosis, tend to be ineffective.¹⁰¹ It is much more effective to tailor interventions, even just to broad physical/mental distinctions.¹⁰²

⁹⁰ Drake, et al., 2009

⁹¹ Huijs, et al., 2012

⁹² Loisel, et al., 2005

⁹³ Dekkers-Sanchez, et al., 2011

⁹⁴ Dekkers-Sanchez, et al., *ibid.*

⁹⁵ Dutta, et al., 2008; Nevile & Lohmann, 2011

⁹⁶ Williams, et al., 2007; van Oostrom, et al., 2009

⁹⁷ Franche, et al., 2004; Clayton, et al., 2011

⁹⁸ van Oostrom, et al., 2010

⁹⁹ Lysaght & Larmour-Trode, 2008; Dekkers-Sanchez, et al., 2011

¹⁰⁰ Matt & Butterfield, 2006

¹⁰¹ Hoefsmit, et al., 2012

Multiple evidence shows that the nature and severity of disability impact the likelihood of returning to work. This suggests at the least that different disability types vary in the level of barrier they create.

People with psychological conditions are least likely to return to work, and the nature and severity of mental disorders are strong predictors of disability and returning to work.¹⁰³

Those with musculoskeletal conditions or sensory/communicative impairments are most likely to return.¹⁰⁴ Where someone has a combination of physical and mental problems they return to work later than those with only one or the other.¹⁰⁵ Conditions or symptoms that are more severe are less likely to result in a return to work.¹⁰⁶

People who do not expect to return to work are less likely to do so.¹⁰⁷ It is unclear why this occurs – some may argue that it represents lassitude and self-defeating behaviour; alternatively, those who do not expect to return to work may be correctly assessing their ability to work in their current condition and the likelihood of it continuing or declining.

The latter explanation fits better with other studies showing that patients are best able to assess the likely duration of their illness,¹⁰⁸ and that the majority of people on sick leave have good attitudes towards work¹⁰⁹ and want to get into work.¹¹⁰ In further support of this, there is evidence that people with common mental disorders are at risk of pushing themselves too far and too fast, rather than too little and too slow.¹¹¹ Sickness absence and returns to work cannot be predicted by general self-efficacy - lower self-efficacy among sickness absent employees is a result of the sickness absence itself rather than a precursor of it.¹¹²

Conclusion

Based on available evidence, recommendations from the BMA and the findings of our extensive consultations, we recommend

- **Early Intervention: Where a person becomes ill or disabled whilst in work, assistance should start within a few weeks of claiming Statutory Sick Pay, i.e. even before a claim for Employment and Support Allowance is made. If the person is not in work, then assistance should start within a few weeks of entering a claim for ESA.**

¹⁰² Huijs, et al., 2012

¹⁰³ Post, et al., 2006

¹⁰⁴ Dutta, et al., 2008

¹⁰⁵ Huijs, et al., 2012

¹⁰⁶ Post, et al., 2006; Hoedeman, et al., 2010; Sampere, et al., 2012

¹⁰⁷ van Oostrom, et al., 2010; Sampere, et al., 2012

¹⁰⁸ Fleten, et al., 2004

¹⁰⁹ Kemp & Davidson, 2008

¹¹⁰ Garthwaite, 2012

¹¹¹ Andersen, et al., 2012

¹¹² Labriola, et al., 2007

- **That an ESA113 or equivalent is sent out to a chosen healthcare professional at the start of every claim, and that regulations 29 and 35 for current and ongoing ESA claims and contribution-based ESA are considered in all cases where:**
 - a) **The claimant has an uncontrolled or uncontrollable illness, or**
 - b) **The claimant suffers from some specific disease or bodily or mental disablement and by reason 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/work related activity.**
- **A supplementary payment for those not expected to work or move towards work, also available to those who engage with future support.**
- **The criteria for access to sickness benefits should take into account the non-medical factors that interact with the medical factors.**
- **That assessment should explicitly focus on what work or job role the claimant is supposed to be capable of doing, what barriers exist and how these can be overcome.**
- **That assessments should occur over several meetings with a consistent caseworker to reduce the snapshot effect and to increase the amount of accurate evidence collected.**
- **Once the process of assessment is complete, evidence should still be submitted to an independent Decision Maker**
- **That the assessor have experience in the relevant disability**
- **Multi disciplinary interventions. An integrated system where the caseworker can advise on benefit entitlement, health services, social care, Access to Work, and has access to local and national information on work support provision, education and training.**
- **Early access to health interventions and control of a Personal Health Budget.**
- **Including the workplace in interventions where possible/applicable.**
- **Disability specific support.**

Fig 3.1 Existing Claimant Journey for ESA

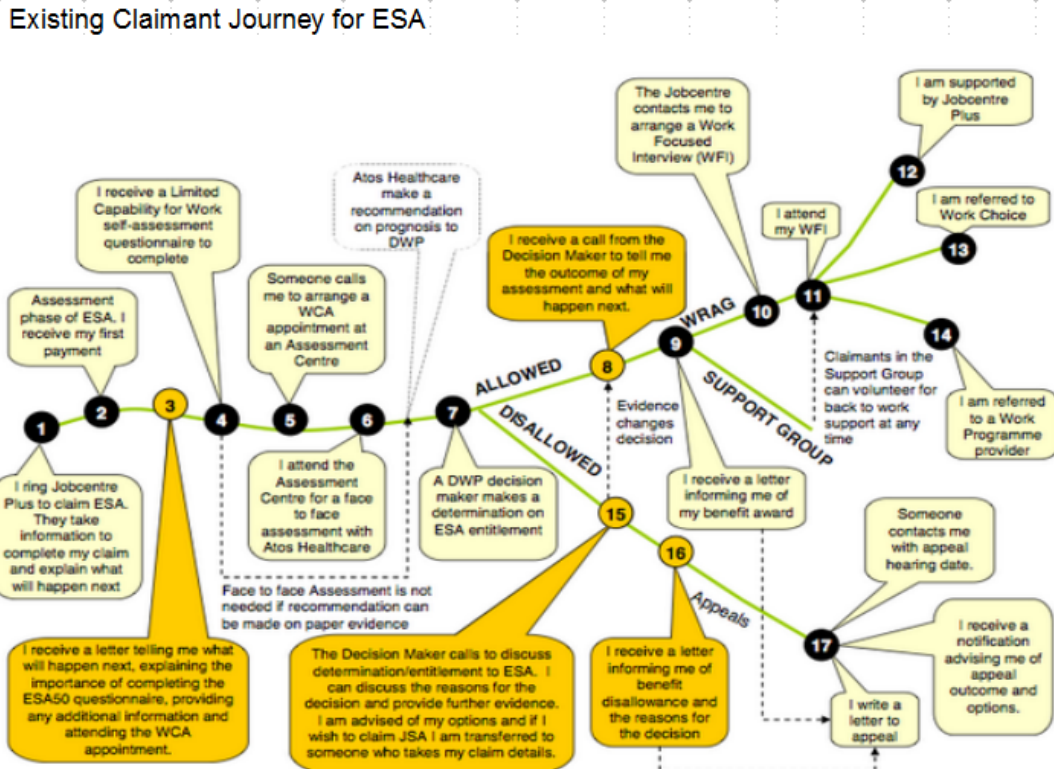
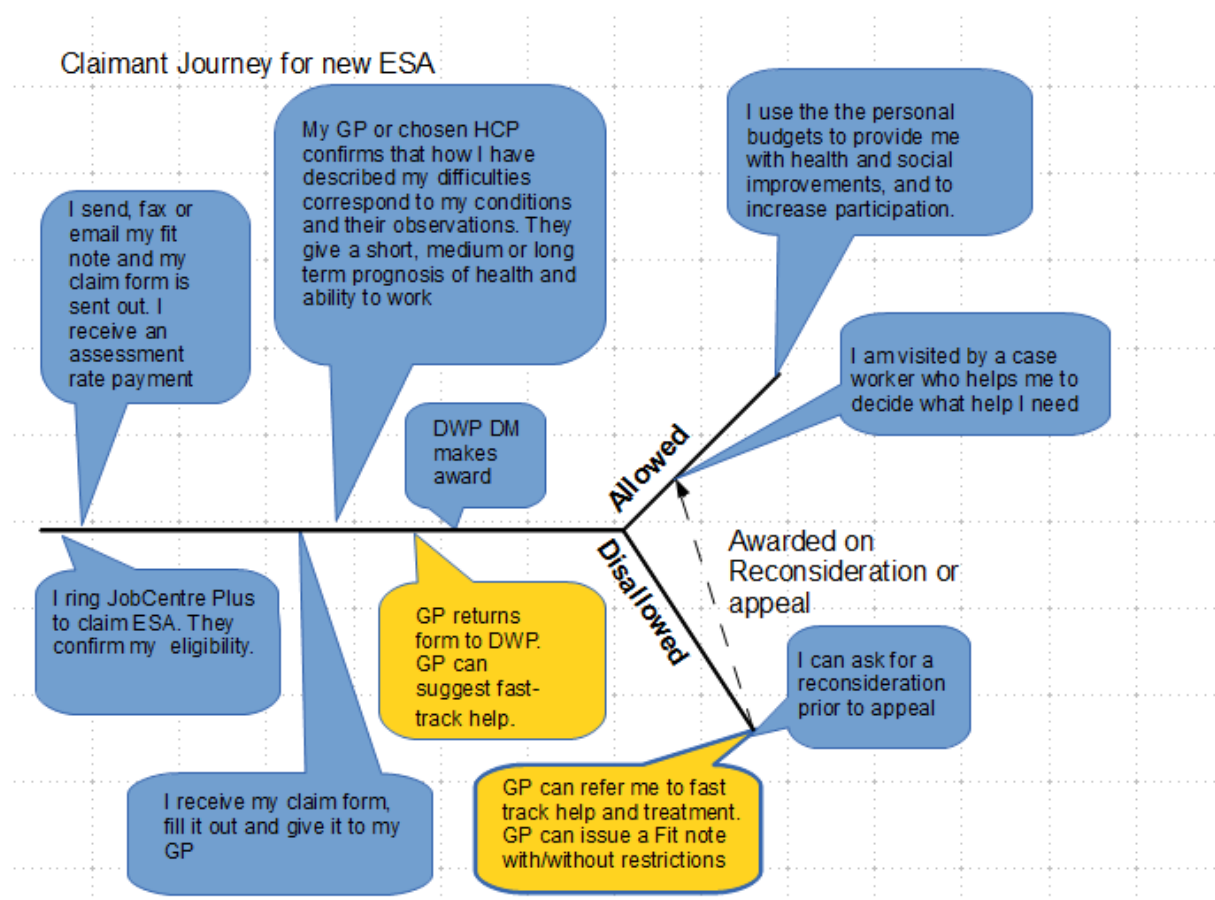


Fig 3.2: Claimant Journey for New ESA



Interim Recommendations

In a further consultation in September 2013,¹¹³ we asked people the question: ‘If you could say just one thing to Mark Hoban (then Minister for Work and Pensions), what would it be?’ We had a meeting arranged with the minister and senior members of the DWP as representatives of the Spartacus Network of campaigners, and wanted to include as many opinions as possible from those who had actually experienced the system.

This is a controversial area. Most campaigners, charities and the BMA want ESA and Work Capability Assessments to be scrapped immediately. However, alternative proposals such as those set out in this report take time to implement and get right. As we’ve seen with ESA, rolling out a system before it is fully ready and tested is disastrous.

We used the comments and suggestions from this consultation to form the basis for a set of interim recommendations that could be implemented immediately, which respondents felt would best mitigate the worst failings of the present ESA system. Several were Harrington recommendations that have not yet been implemented. (Denoted by “H”)

However, we want to state very clearly here, that implementing these interim suggestions in no way makes ESA or WCAs “fit for purpose”. They are not a substitute for full and comprehensive reform as suggested throughout this report. They merely mitigate the very worst failings of the current system, making it at least a little safer and fairer until a fully reformed system can be rolled out.

1) Mandatory Reconsideration

This was the third highest theme in the responses to the Spartacus consultation (‘What one thing would you say to Mr Hoban?’). It is important to note that all responses to the survey were spontaneous – no prior suggestion of what people might want to say was given. As of 28th October 2013, claimants who are found “Fit for Work” and disagree with the decision must undertake a mandatory reconsideration (MR). This allows the DWP decision maker to look at the decision again, before the unnecessary stress and costs of an appeal. However, the DWP argue, that as the claimant has been found fit, they are no longer entitled to a payment of ESA. Benefit payments will therefore stop until MR has taken place. Unfortunately, the DWP have refused to set a time limit on how long this can take. Whilst they argue that claimants can claim other subsistence benefits during this period in practise, this won’t always be the case. For example, many with partners who work will not qualify.

“[I would ask Mr Hoban] to pay ESA at assessment rate during a DWP reconsideration, which could take months. Too many sick people having to appeal a fit to work decision will be too sick to get to a Jobcentre regularly to sign on for JSA. This is a catastrophe waiting to happen.”

“Mandatory reconsideration puts claimants in ‘decision limbo’ and at a significant risk of destitution. Claimants should not be bereft of income pending appeal.”

¹¹³ <http://diaryofabenefitscrounger.blogspot.co.uk/2013/09/if-you-could-say-just-one-thing-to-mark.html>

There are also serious questions to be asked about whether or not a claimant who has limited capability for work (LCW) can in fact legally sign on for JSA, as this involves agreeing to capability for work.

There are concerns around the accuracy and quality of WCA reports. Possibly as a consequence of this, the appeal success rate for ESA is higher than it is for any other benefit. Furthermore, 60% of those winning their appeal were originally awarded 0 points. Given this, it seems reasonable to allow people to retain benefit during reconsideration.

“Reconsideration was rejected but the report was missing all the medical evidence I had sent. The decision maker eventually changed the decision to the support group. I was receiving threatening letters from G4S and JCP about appointments which were impossible to attend.”

In the workplace, even where gross negligence is suspected, the worker is suspended on full pay until a definitive outcome is reached. **We recommend the same process should remain for ESA.**

This would very much improve the perception of ESA, by returning a small amount of confidence in the system. It would also help those who are putting in claims for ESA to feel that the government supports people who are too sick to work.

2) Accessible Centres (H)

We are aware that the DWP is working to improve centre accessibility, and that most turn-aways are linked to just six centres.¹¹⁴ Nevertheless, there remains a perception amongst disabled people that Atos does not make reasonable adjustments to the disability of their clientele, and too often turn down reasonable requests for home visits.

“ATOS assessment centres should be accessible. If the nearest is not then a home visit should be offered as routine rather than claimant obliged to travel long distances. Home visits should be more widely available and offered.”

Making this option more widely available and increasing awareness of the possibility and method of requesting a home visit (or alternative venue) from Atos will improve disabled people’s perception of the system and reduce the stress associated with this issue. Meanwhile, as Mr Hoban said to the Work and Pensions Committee regarding the six ‘problem’ centres, it sounds as if the administrative process relating to those centres is not currently working. Improving the administrative process should be relatively easy to do at little cost to the department, and would improve the perception of Atos and the DWP as well as reducing delays caused by turning people away.

¹¹⁴ Work and Pensions Committee, ESA and the WCA, Oral and Written Evidence 21 Nov 2012: <http://www.publications.parliament.uk/pa/cm201213/cmselect/cmworpen/769i/769i.pdf>

3) Minimum Limits on Re-assessment

Disabled people find the ESA process stressful and detrimental to their health. In a Disability Benefits Consortium survey in 2012, 78% of respondents agreed or strongly agreed that stress or anxiety made health worse (up from 69% in 2010); while the proportion who 'strongly agreed' alone rose to 57% (from 44% in 2010). In the same survey, 86% agreed that applying for ESA was stressful, up from 79% in 2010.¹¹⁵

In the two Spartacus surveys, stress was (1) the most and (2) the second most frequently identified concern. In both surveys, answers were spontaneous and not selected from a list.

Many respondents commented on a "conveyor belt" system of claim, assessment, rejected claim, successful appeal – only to find that the whole process immediately started all over again.

"What on earth is the point of repeated assessments of people who are CLEARLY not going to get better? What is the point of reassessing someone shortly after they have won an appeal?"

"Why repeated assessments? This is so hugely emotionally and physically damaging to people."

With this in mind, we recommend a minimum assessment period of 1 year for those in the WRAG and 2 years for those in the SG.

This would also have a significant impact on the backlog of cases currently awaiting a decision, as well as the number of cases going to appeal in future.

4) Mental Health Champions (H)

As we have seen, Professor Harrington recommended the introduction of Mental Health Champions in every assessment centre. However, at the time of writing this report, there are just 60 placed on a regional basis, not in each assessment centre.¹¹⁶

Government have argued that these 60 champions are available to give telephone advice to HCPs (Healthcare Professionals or assessors) at any centre, but in practice, both HCPs and claimants do not feel that is adequate.

Unfortunately, neither have disabled people and their groups seen evidence that the Mental Health or Mental Function Champions are improving the system for disabled people. There remains concern that people who are not trained mental health workers do not and cannot understand the impact of a mental health condition on an individual's ability to work.

¹¹⁵ Response to WCA independent Review - Year 3 call for evidence, September 2012

¹¹⁶ Harrington, 2011

“All assessors should be qualified to assess the condition in front of them... Mental function champions on the end of a phone that may or may not be contacted is simply not good enough in a modern welfare system.”

We recommend ensuring that, as recommended by Professor Harrington, there is a champion in every assessment centre with considerable and relevant mental health experience.

5) End the Division between Cognitive and Physical Descriptors

The DWP has repeatedly stated that the WCA is “based on the premise that eligibility for ESA should not be based on the diagnosis of a specific condition, but rather on the way that the condition limits an individual's functional capability.”¹¹⁷

Policy intent is clear that mental, cognitive and intellectual descriptors could be met by physical conditions. Whether the effect of a mental condition on a physical symptom could be considered was not explicitly permitted, but given that it was also not explicitly forbidden – as had been the case for Incapacity Benefit – the case law is that there is no such dichotomy.

However, at the beginning of 2013, the government changed the way people’s conditions are assessed by dividing health problems into two separate boxes: ‘physical’ and ‘mental’. When looking at what tasks people can do, only the ‘physical half’ of the test will apply to those with physical disabilities. The same goes for the effects of treatment: for example, if a claimant is taking mental health medication, only mental health side-effects will be looked at.

“There is... direct discrimination against those with conditions such as Parkinson's and MS, which involve a combination of physical and cognitive impairments, that the points due for one or the other are bizarrely disallowed.”

This dichotomy has the potential to be dangerous as major symptoms and/or side effects could be ignored. It is also contributing to the perception that the government does not want to help people, and is trying to find ways to get people off benefit even though those people cannot work. To remove this false dichotomy would be very simple, and could help reassure claimants that the government is committed to instituting accurate assessments. More information is available in the attached report on this mental/physical dichotomy.¹¹⁸

We recommend that this dichotomy is removed.

6) Recording Assessments (H)

¹¹⁷ Grayling, Hansard, 10 October 2011 : Column 230W

<http://www.publications.parliament.uk/pa/cm201011/cmhansrd/cm110131/text/110131w0004.htm#11013139000675>

¹¹⁸ <http://diaryofabenefitscrounger.blogspot.co.uk/2013/01/esasos.html>

A significant proportion of respondents to the Spartacus surveys thought that audio recording of assessments is a good idea.

“Quite simply the biggest change with the biggest knock-on effect on everything else is this: all assessments must be recorded. It should be mandatory for all assessment centres.”

“Offer recorded assessments as a matter of course, to protect assessors and decision-makers as well as claimants and those assisting them.”

Although very few in the past have asked for a copy of their assessments, as Dame Anne Begg pointed out, it is the recording itself, not the possession of a copy, that gives the reassurance that there is evidence available in the event of needing it.¹¹⁹

Given this and the increasing demand for audio assessments, Professor Harrington recommended that audio recordings of assessments be done for all assessments as a matter of routine. Should the claimant not wish for an audio recording it would be simple to accommodate this.

Each ESA appeal is estimated to cost £400, based on answers recorded in Hansard. Consequently, if appeals were cut by 5% by using audio recordings, over 600 machines could be purchased, which is an average of four per assessment centre.

We recommend that audio recording of assessments becomes standard practice, with the option to opt out if claimants so choose.

7) EBR – New descriptors

This report gives endless evidence on why the current descriptors for ESA aren't working. For instance, the employment rate of people who started a claim for ESA is low compared to the employment rate of people who start a claim for Jobseekers Allowance (JSA).

Employment rates 12-18 months after starting a claim are:

- 39% who end their claim before a decision is made
- 25% who are found fit for work
- 9% who go into the work-related activity group
- 10% who go into the support group

In comparison, 80% of Jobseekers leave JSA within 6 months of starting a claim.

Consequently it would appear that the descriptors are too harsh, with many people being found fit for work who cannot work or can only work with support, and many people who cannot undertake 'work-related activity' being placed in the WRA group.

¹¹⁹ Work and Pensions Committee, ESA and the WCA, Oral and Written Evidence 21 Nov 2012:
<http://www.publications.parliament.uk/pa/cm201213/cmselect/cmworpen/769i/769i.pdf>

"[ESA] descriptors are far too rigid and inflexible, and don't adequately cover variable conditions."

"The fact that so many people had their decisions of "fit for work" overturned... shows without a shadow of doubt that [ESA] is simply not working."

We understand that the government is undertaking a review and strongly urge that all findings, including detail of the data analysis (but not of the participants themselves), are made available as soon as possible. **In the meantime, we recommend that the interim findings and progress on this issue so far should be published.**

8) Health professional evidence (H)

In the September Spartacus consultation, this was the single most common response to the question "What one thing would you say to Mr Hoban?"

The Harrington Review said that, "There should be a requirement in every claim to consider seeking further documentary evidence and, if that evidence is not sought, then the decision not to should be justified."¹²⁰ Mr Hoban had said that such evidence should be submitted as early as possible, and not left until an appeal. Charities and disabled people have repeatedly said that evidence from GPs and other health professionals who care for the claimant should form a much bigger part of the assessment.

"Medical evidence from the claimant's own GP, nurse specialist or consultant must be taken into account (whether it is provided by the claimant or sought by DWP/ATOS)."

"Please make decisions based on evidence from the doctors who actually know us and our conditions rather than using non-specialist and non-medically qualified assessors."

This would be very simple to add in. The claimant's nominated GP or health professional(s) can be sent a form (ESA113) asking for their view on the risks of going to work (i.e., whether work might cause a decline in health) and for their views on the claimant's abilities on the limited capability for work and limited capability for work-related activity descriptors.

In addition, there are 2 special regulations that can exclude a claimant from the start of a claim on the basis of risk (Sections 29 and 35). It would also be an easy matter to ask GPs and health professionals if, in their opinion, the patient would be at significant risk if the assessment process were taken further. If this is considered to be the case, an award of ESA could be made without further process.

We recommend that both options are available at the start of every claim, giving GPs/health professionals plenty of time to respond. It also should be made clear that any such forms must be returned in all possible cases.

¹²⁰ Harrington, 2012

9) Time Limiting

The one year time limit of contributory ESA for those in the Work Related Activity Group (WRAG) only affects families where somebody works, people with savings and people who have already paid into the system.

The means test is set at just £7,500 and though the government argue that many people will be able to transfer to other benefits, many will not. Impact Assessments predict that between 240,000 and 700,000 people will lose support from this measure alone.

Time limiting acts as a disincentive to those partners struggling to remain in work and care for a sick or disabled relative, and removes the contributory principle from this fundamental strand of our social security system.

Our research shows that people themselves are the most effective at assessing the severity and duration of their conditions and that those removed from support before they are ready often simply return to the benefit later on. There is nothing to be gained from restricting the numbers who can access benefits in this way: instead, it simply creates unnecessary assessments and re-applications.

We recommend that the one year time limit on ESA is reconsidered as a matter of urgency.

Further Evidence on Participation Barriers

Fig 2.1: Participation Restrictions

Additional barriers are often described as Participation Restrictions.

An adult has a participation restriction if they experience at least one barrier to taking part in any of the following life areas:

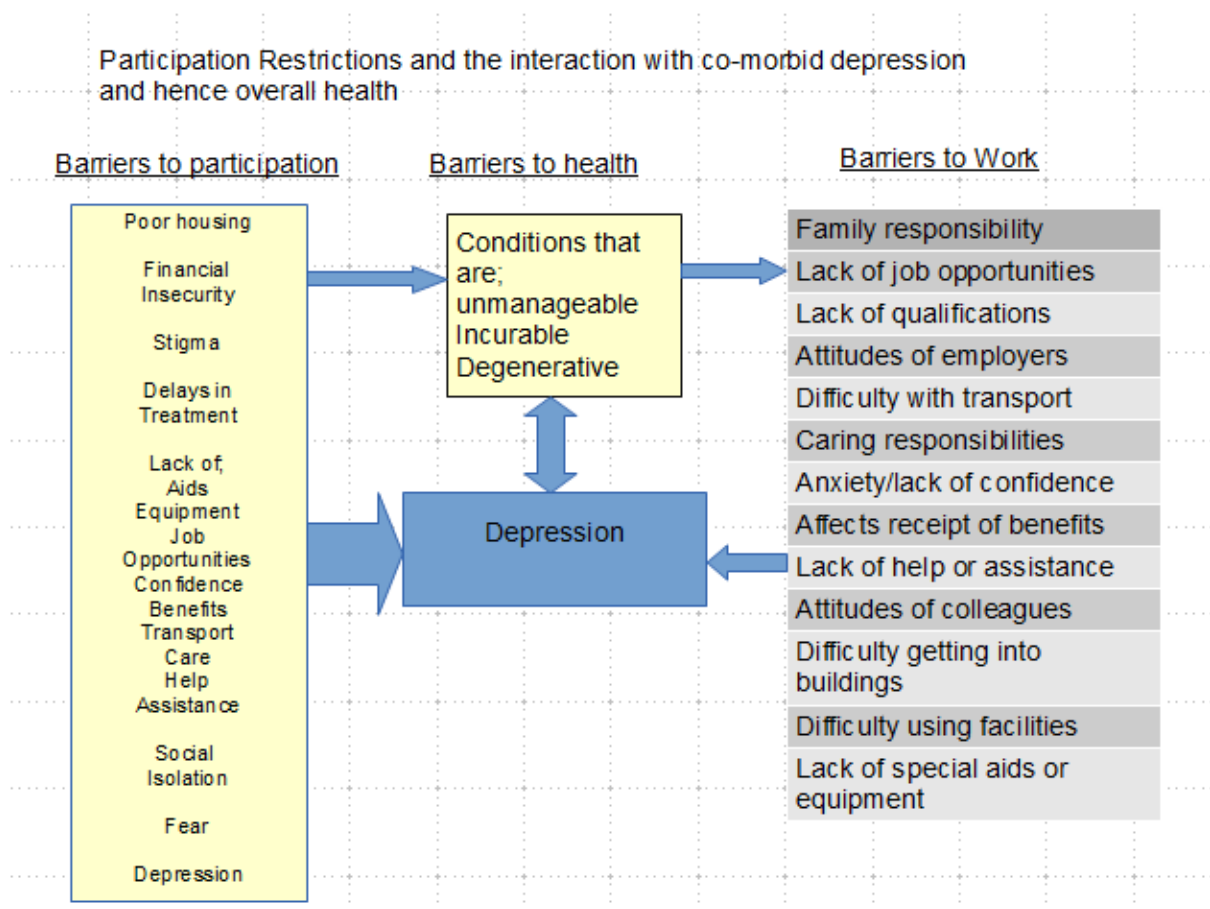
- education and training
- employment
- economic life and living standards, for example being able to afford usual expenses or make loan repayments
- transport
- leisure activities
- social contact

Fig 2.2: Participation Restrictions in Key Life Areas

Participation restrictions in key life areas

- 16 per cent of adults with impairment experienced barriers to **education and training opportunities** (that is, the learning opportunities they had) compared with nine per cent of adults without impairment.
- 57 per cent of adults with impairment experienced barriers to **employment** (that is, in the type or amount of paid work they did) compared with 26 per cent of adults without impairment.
- 75 per cent of adults with impairment experienced barriers to using **transport** compared with 60 per cent of adults without impairment.
- 44 per cent of households with at least one person with impairment experienced barriers to **economic life and living standards** (that is, being able to afford expenses or make loan repayments) compared with 29 per cent of households without any people with impairment.

Fig 2.3: Participation Restrictions and the Interaction with co-morbid depression and hence overall health



The Work Programme and ESA

When ESA was first introduced it was broadly supported by disabled people's organisations because it promised a step change in support to help disabled people into work.¹²¹ The emphasis was on support tailored to the needs of individuals, and capable of addressing complex needs. Hopes for achieving personalisation were pinned to the new commissioning model for employment support, recommended by Lord Freud,¹²² which is now the Work Programme.

The key aspects of the Work Programme are:

- A **Black Box approach** where minimum service prescription allows for flexibility and innovation in service design.
- **Long term contracts** are designed to support participants throughout their employment journey.
- **Payment by results** and the **differential pricing** mechanism are supposed to reflect the fact that some claimants are harder to support and incentivise providers to direct resources through supply chain of specialist subcontractors at those with complex barriers.¹²³ The highest payment group from ESA participants, made up of the long term sick transferred from Incapacity Benefit, is worth a maximum of £13,550 to providers.

However, after its first two years of operation, job figures for ESA claimants supported by the Work Programme are falling far below expectations.¹²⁴ We asked for the experience of disabled participants of the Work Programme to try and understand why it has not lived up to its promise.

The Work Related Activity Group for ESA

The Work Capability Assessment (WCA) for ESA sorts those who qualify for support into two groups. The Support Group is designed for those judged incapable of work, and grants unconditional support. The Work Related Activity Group (WRAG) includes an expectation for claimants to prepare for work as a condition of receiving benefits. Most WRAG claimants will be mandated to the Work Programme. New ESA referrals make up 9% of all referrals to the Work Programme.¹²⁵

The Department for Work and Pensions (DWP) has not consistently defined the status of the WRAG in relation to the job market. At times it states claimants in the WRAG are not fit for work but expected to recover and return to work within a given period. At other times it has implied that claimants in the WRAG are capable of work. In practice claimants are placed in the WRAG by default, when they accumulate sufficient points under the eligibility criteria to

¹²¹ DWP, 2006

¹²² Freud, 2007.

¹²³ ERSA, 2012

¹²⁴ DWP, 2013; ERSA, 2013

¹²⁵ DWP, 2013

be deemed unfit for work but do not meet one of the narrow and precise criteria for entry into the Support Group.

Work Programme ESA outcomes in context

Job figures for ESA claimants supported by the Work Programme are falling far below expectations. DWP collected data from June 2011 to June 2013 show that out of 186,440 attachments to the Work Programme from the three main ESA payment groups just **3.34% achieved a Job Outcome**¹²⁶, that is employment sustained over at least 13 weeks. The DWP estimates that **without intervention**, 5% of ESA claimants would find work by themselves within one year.¹²⁷

The Job Outcome figure for the **long term sick or disabled**, i.e. those transferred onto ESA from previous Incapacity Benefit is **0.98%** for the same period.

The basis for mandating ESA claimants to the Work Programme is that *“The old incapacity benefits system condemned too many people to a life on benefits with little hope of moving back to work.”*¹²⁸

However, this depiction of the labour market inactivity of previous IB claimants breaks down upon further inspection. Data collected for the DWP from 3,000 Incapacity Benefits claimants between 2008 and 2009 show that **within 13 months of their claim, 25% had been in work at some point.**¹²⁹

This measure is different to a Job Outcome, but equivalent to a Job Start. Data collected by ERSA shows that **within 21 months 15% of ESA referrals to Work Programme had achieved a Job Start.**¹³⁰

In short, Job Start rates among IB claimants were significantly higher before ESA was introduced. Yet a report concluded that the previous employment support scheme for people on Incapacity Benefit, Pathways to Work, had no statistically significant impact upon employment.¹³¹

Pathways to Work performed little or no better than the Work Programme. So how can these previously higher Job Start rates be explained? Perhaps some of the discrepancy can be attributed to a more buoyant job market, but it could also be that the Work Capability Assessment has achieved what it set out to do, that is to remove from the ESA caseload all but the most severely impaired.

¹²⁶ <https://www.gov.uk/government/organisations/department-for-work-pensions/series/work-programme-statistics--2>

¹²⁷ DWP, 2013c

¹²⁸ See, for example, BBC, 2012 (29 September): Disability tests opposed by dean of St Paul’s Cathedral: <http://www.bbc.co.uk/news/uk-politics-24321105>

¹²⁹ Hayllar & Wood, 2011

¹³⁰ ERSA, 2013

¹³¹ Knight et al., 2013

An obvious point, not often made, is that people on ESA are, on average, more unfit for work than people on Incapacity Benefit were.

To qualify for ESA you must score 15 points in a Work Capability Assessment (WCA) However, the distinction between the WRAG and SG is often negligible. Claimants must still score 15 points, but to qualify for the Support Group, all 15 points must be scored under one descriptor. Someone could score 40 points across a range of descriptors, indicating multiple barriers to work, but still be compelled to prepare for work, whereas someone scoring 15 in one descriptor would be exempt from conditionality.

This leaves many who score perhaps 12 or even 6 points or less, but who still have significant impairments and barriers to the workplace. Nonetheless, under the current system, they are judged to be “fit for work” and so treated exactly as jobseekers. We will see in the following section how even those who do score 15 points and are placed in the WRAG are conflated with jobseekers. Those scoring less than 15 points will always be at a significant disadvantage in the job market, yet will receive none of the tailored support they may still need to find or return to work.

1. Conditionality regime does not address barriers to participation

ESA claimants enter the Work Programme with the promise of unprecedented support tailored to their complex needs, but also with an unprecedented degree of conditionality to enforce participation in Work Related Activity (WRA), despite the fact they on average have a greater degree of mental or physical impairment than the previous IB cohort.

Sanctions for failing to participate in mandatory work related activity rose to £71 per week in November 2012, leaving just £28.50 per week in income. The role of the Work Programme adviser is to report a failure to participate, known as a Compliance Doubt, to a Labour Market Decision Maker at the DWP/Jobcentre, who decides whether to impose a sanction. A total of 173,000 sanctions decisions were made between October 2008 and June 2013, of which, 76,000 resulted in a sanction.¹³²

Mandatory work related activity for ESA claimants in the WRAG may consist of anything that a Work Programme adviser considers reasonable, apart from seeking work. The DWP offers detailed guidance to Work Programme providers in deciding whether a “mandated” activity is reasonable.¹³³ These chapters of regulations on Mandation and Reporting a Compliance Doubt make no mention of the type or degree of mental and/or physical impairment that characterise ESA WRAG claimants, other than that they “may have a health condition”. Yet the strict eligibility criteria, or descriptors, in the WCA require a degree of impairment to be present which is likely to present a barrier to participation.

“I have Colitis which is a long term illness affecting my digestive system. It means that I can often find myself housebound and don't always have warning of when my bowels will fail. I had to use the bus to get to the Work Programme offices which

¹³² DWP, 2013d

¹³³ DWP, 2013b

were in the next town over. From my front door to theirs, took roughly 50 minutes. You can imagine how difficult and stressful that was given my bowels may fail and there's no toilets on a bus."

Some participants found their adviser to be accommodating to their impairment:

"The A4e office I had to attend took about 50mins for me to get to via bus & slow walking (I use a crutch). I still remember the look of disbelief on the face of the A4e adviser when I pulled out a large plastic bag of my daily medicines including morphine. He said that given my pain & mobility difficulties, he would conduct future appointments by phone to save me from coming into the office. For that I was grateful."

But for others, the prospect of not being capable of attending a programme with sanctions attached to it is very distressing. One respondent experiences severe anxiety and agoraphobia, well documented by professionals who have supported her over 15 years:

"There is no way that I can mentally or physically attend this work programme placement. If I can't function in a supermarket or shop or any place unless my mother is with me at all times, how can I be expected to go there? I don't want to imagine the horrors of having a massive panic attack in a public place with strangers around. Last time that happened in a work environment, I spent the afternoon in A&E"

In some cases, where the impairment is not immediately visible, Work Programme advisers have disputed its very existence:

Sarah was reported to Jobcentre Plus for failing to participate even though she informed her adviser beforehand that she was unable to attend a mandatory information session due to a fluctuating health condition. Her advisor said *"How do you I know if you're really sick or just lying: anyone can say they're sick?"* Sarah pointed out that she was receiving ESA on the basis that she has a chronic debilitating illness. The adviser nonetheless made her obtain a Fit Note from her GP to prove that she had a health condition.

2. Support service does not refer to the claimant's assessment of needs.

One may assume there could be no basis for disputing the nature or severity of a participant's impairment once they have undergone the WCA. The presence of impairment-related barriers to work is listed in the DWP's decision report (ESA85) for awarding ESA.

However, this report is not communicated to Jobcentre Plus or Work Programme providers. In his second independent review of the WCA, Professor Harrington made recommendations about smoothing the claimant journey, particularly the "baton pass" between the WCA and Personal Advisers¹³⁴. It is difficult to see how support can be personalised and tailored to the individual if it does not refer to the original assessment of needs.

¹³⁴ Work and Pensions Committee, 2013

“At my first work focussed interview I took a copy of my ESA85, in case my adviser didn’t have it. So when she asked me what my problems were I handed her the report. But she pushed it away saying “I can’t read that dear, I’m not even qualified to put a sticky plaster on”. She went on to record that my main obstacle to work was lack of confidence, no mention of any health problems.”

“From the day I began the Work Programme to the time I left, I was treated the exact same as a JSA claimant, despite things being very different for most people on ESA, including me. I was always the one who brought up my ESA status, my illness, how my disability affected me and why that affected my ability to work and only do certain jobs. Each time it was simply ignored.”

“My adviser freely admitted at our first interview that not only did she know nothing about M.E. but that she hadn't even heard of it. Quite how she will be able to 'support' me whilst knowing nothing about what I'm up against is anyone's guess.”

3. Conflation of disability with long term worklessness

The Black Box contracting model means that the DWP does not specify what employment support for disabled people receiving ESA should look like. In its guidance to Work Programme providers the DWP advises only that: “The activity should be something that will help participants by enhancing their employment prospects and developing skills and disciplines associated with a normal working environment (e.g. attending on time, carrying out tasks, working as a team, interpersonal skills etc.) Those skills also include "behaviours" acceptable in a place of work.”¹³⁵

In the absence of guidance about the functional limitations of ESA WRAG claimants, and without access to participants’ WCA assessment reports, Work Programme providers seem to be focussing their interventions almost exclusively to addressing basic jobsearching skills and developing a work ethic.

*“Suggesting I train is all very well, but that doesn't help me find a job with someone who doesn't mind that I **will** have seizures in the workplace.”*

“I would much prefer that they understood that my CV bears no relation to any kind of work I could possibly do (due to severe pain from Fibromyalgia), so what would really be the good of sending it with job applications?”

“We were told what services they offered - like getting your GCSE's in Maths/English, Learning to use a Computer etc., but none of what they were offering, if I was physically able to attend on a regular basis, was relevant to me. The crux of the matter is that having ME/CFS means I don't know how I will be from day to day. If

¹³⁵ DWP (2013), *Work Programme Provider Guidance* <http://www.dwp.gov.uk/docs/wp-pg-chapter-3a-22-october-2012.pdf>

I've been out, like going to the Jobcentre, the next day I'm floored, literally all I can do is shuffle between my bedroom and bathroom."

Tessa has epilepsy. She was surprised to find herself in the Work Related Activity Group but decided to grasp the opportunity for employment support. She quickly became disillusioned with the service: *"The tone of the letters I received from DWP were aggressive and seemed to assume that I was not working through choice rather than disability. They certainly did not appear have anything in place to understand or help me with my individual barrier to work (mostly unconsciousness). They offered basic skills, basic computer work or a CV writing service. If these were all I needed then I would have been working already!"*

Jane said of an Information Session for ESA claimants she attended: *"We were all treated like illiterate 3 year olds who just needed to 'cheer up'. No-one's physical issues were ever addressed, only glossed over or ignored."*

4. Disabled people's skills and motivation lost

The 18 lead providers of the Work Programme, almost solely from the private sector, are not expected to have expertise in disability employment support. However, the commissioning structure of the Work Programme is designed to give them the financial incentive, to buy in specialist "end-to-end" support for disabled people. Research shows the differential pricing mechanism is not producing this result.¹³⁶ Providers are not buying in expertise to anything like the degree expected and instead are "parking" clients further from the job market and directing resources at the most job-ready; i.e. those on JSA without complex needs.

The case studies we received show that disabled people themselves often have considerable expertise, not only in identifying their own barriers to work but in finding solutions. But their initiatives are not followed through by the Work Programme in the way they could be.

James, 49, has mental health problems and desperately wants to find work as he feels it would improve his health, as well as his financial situation under strain from the under occupancy charge or "bedroom tax". He has taken several initiatives of his own to improve his job prospects, including volunteering in a drop in centre, a course in care work, and a college course to train in photography and digital imaging. *"The main problem I have is getting an employer to see past an employment gap and mature/middle age. I have vast life/work experience that could prove valuable to a future employer."* Since January 2013 James has only seen his Work Programme adviser once. He has found a local mental health organisation in Birmingham that offers employment support. *"I am hoping they will help me get back into some kind of work. I feel the ESA/Work Programme system is not properly set up to help people like myself that have limited work capability"*.

¹³⁶ Rees et al., 2013

Valerie, 58, was called to an ESA Experience session at Ingeus in 2012. *“I explained that I suffered from agoraphobia and also had arthritis of the spine, hips and knees which causes me to be in pain all the time. I told them that I had tried to think of work I could do from home and gave them several examples. They responded enthusiastically. I explained that all of my ideas had come across stumbling blocks which were either financial, legal, or attainability issues. They kept saying they could get some business cards printed or help create a website. But there was no feedback whatsoever on the problems I had cited.”*

Danielle who suffers from Fibromyalgia, has attempted to overcome barriers to conventional workplace through self-employment. *“I was dropped from the work programme after a year of their self-employment programme because I didn't meet the minimum income floor for my business despite doing the hours. The provider got paid for a successful outcome but I've been left struggling with my business with no support from them or Access to Work. The Work Programme providers have little to no self-employment training or training in tax, insurance, benefits. They referred me to a so called professional who basically told me to Google the answers to my questions. He left me to do my business plan by myself yet billed the Work Programme for supporting me.”*

5. Conditionality can move claimants further way from work

Some participants told us the distress they felt at being mandated to activities they could not perform, and the fear caused by the strongly worded threats of sanctions which accompany communications from Work Programme providers, has had a significant impact on their wellbeing and mental health. Those with pre-existing mental health difficulties are undoubtedly the worst affected. Those with physical impairments report that the psychological strain has affected their health. They feel less able to envisage a return to work as a result.

Noreen, who suffers from agoraphobia, says: *“I think it's cruel to harass someone who isn't fit to work and who can't get out of the house without a great deal of support to attend a work placement when it's simply impossible. At the moment I am ignoring the letters because I can't cope with them. I have barely slept and I'm experiencing a lot of horrible anxiety symptoms. Rather than helping me they are making my condition much worse.”*

Jackie, who has Fibromyalgia echoes this: *“I have an appointment tomorrow, so I will spend my little amount of energy going through the motions, then come home annoyed, have a sleepless night and be ill for the next few days.”*

Sadly, for Sarah this has entailed a huge loss in her previous quality of life which, despite being unable to work, included activities that contributed directly to society and provided her with fulfilment:

Since she became ill with ME/CFS and had to leave her job as a training and language consultant, Sarah has managed to gain a counselling qualification and has been

working pro bono three hours per week for a local charity using her counselling skills. However, the stress and workload of trying to comply with WRAG conditionality and her battle against two unjust sanctioning referrals have contributed to deterioration in her health. Sarah has had to give up her voluntary work and now devotes her limited energy to navigating the benefits system and sanctions regime.

Lisa explains how the distress and fear of losing her benefits under the Work Programme have compounded her anxiety from the accumulation of changes to sickness and disability benefits: *“The last couple of years have seen a significant decline in my physical condition and the appearance of symptoms that I've not had before and it's partly due to the endless stress of needing to claim this benefit and the worry of losing it. It has put a tremendous amount of strain on my emotional & mental health.”*

Nancy is only eligible for National Insurance credits as she has been timed out of ESA and disqualified by means testing. She has decided not to claim them anymore *“I contacted DWP today to end my ESA claim. I couldn't face the large brown envelope of doom as I call it, with the ESA50 form enclosed; the appointment letter for the ATOS medical which is a 40 minute taxi ride away from home; having to pester my medical team to provide evidence on my behalf. I was asked if I had a job, I replied 'no'. I can't cope with the stress and hassle of having DWP and A4e on my back all the time, it's making my illness worsen.*

6. A poor customer service to vulnerable clients

Not one of the respondents to our call for evidence felt that their advisor made an attempt to offer a personalised service that genuinely attempted to address their limited capability for work. The Work Programme is experienced by those furthest from the labour market, as a box-ticking exercise for providers to fulfil their contract with the DWP. Its standards of customer service are often appalling:

“While on the WP they spent hardly any time with me. All the time I spent with someone face to face was about filling in forms or handing over information or answering dubious and often insulting questions. The first 2 times I came to meet my assigned adviser I was told she was off sick or that they'd double-booked. Eventually I saw an adviser and she wanted my CV, talked about some courses they had which were irrelevant to me and spoke of work experience which she said 'we could discuss later'. Then the computer broke down and she had to end the appointment. The next time I arrived to meet my adviser I waited long past the agreed time and then was told the computer system had broken down and they would rearrange my appointment for another day. I left after that to try Work Choice.”

“The phone calls were scheduled 6 weekly but never lasted longer than 2-3 mins. I would receive an appointment letter by post with a date & time but the adviser never stuck to the time so I felt I was trapped at home waiting by the phone all day. These appointments were described as being 'work related activity' and were mandatory. I was told that if I didn't answer when they rang me, I would be sanctioned.”

“There are wrong letters sent, the wrong information given, the information you want but nobody knows and being asked to be at two mandatory appointments at the same time”

We have seen in earlier sections that excessive conditionality and punitive sanctions are counter-productive. We’ve shown that the barriers to work faced by ESA claimants are overwhelmingly health or impairment-related, and not grounded in motivation or attitude.

Recommendations

We therefore recommend that mandation of ESA claimants to the Work Programme in its current structure is ended immediately.

We believe that clients should control their own back to work support budgets as they are the best at assessing what help they need, what barriers they face and what interventions might be necessary to return to work.¹³⁷

This might include rehab, treatment, aids and adaptations, training or further education, self-employment advice or confidence building courses.

We recommend that caseworkers/support workers have access to all available information on local work support, schemes and training/education and voluntary work/work experience. Similarly, any national charity or government backed schemes that might be helpful.

Whilst it is easy to see why a payment by results system was attractive to the public purse, it has merely squeezed smaller, specialist providers out of the market, leading to less tailored support – the very opposite of what it aimed to do.

With personal budgets and user control, we would expect to see quite rapid, local, good quality, proliferation of services as smaller, specialist providers come back into the market and fill the gaps currently left by the Work Programme

Whilst many of the recommendations in this report may take years to fully implement, we believe that this quite radical change could be taken very quickly and the market would naturally adjust to provide much more suitable, tailored support.

¹³⁷ See also: DRUK, 2013

The Future of Work

As we have seen, ESA was designed to support people with illnesses, degenerative conditions, mental health conditions and disability into work wherever possible. We have also seen that the structure, assumptions and ideology behind the benefit has failed on the whole to achieve that goal in any significant sense.

Just 4-5% of ESA clients taking part in the Work Programme currently find sustained work of at least 13 weeks.¹³⁸ More move into work through their own efforts¹³⁹ and many return back to ESA, particularly if sanctioned from or otherwise removed from ESA before work is a realistic option.¹⁴⁰

Many schemes and trials have attempted to reduce the IB/ESA budget through off-flows but few have shown degrees of success that make the eye-watering amounts of money involved efficient or justifiable.

This section aims to look at why these difficulties exist, as well as to offer real solutions for the future.

Most people use ESA as a temporary benefit to see them through short periods of ill health or disability. 94% either stop their claim or find work within 2 years.

Traditionally, the ESA cohort has been seen as a static lump: 2.5 million people or so who claim long term support. This is completely misleading and simply wrong. The majority of people make claims, recover and move on: very few become long term claimants. Yet over time of course, these long term claimants start to make up an ever increasing proportion of the overall caseload.¹⁴¹

This shows that it is those with the most longstanding and troubling conditions who will benefit most from any involvement aimed at re-entering the workplace with the right support.

We must now accept that, on the whole, that support has failed. Common misunderstandings have meant that we have fallen into the trap of believing that these long term claimants do not want to work. In the vast majority of cases, this could not be further from the truth. It is more accurate to say that either

- 1) Claimants cannot work sustainably;
- 2) Claimants cannot work reliably enough to “make work pay”;
- 3) Work does not exist that the claimant could do;

¹³⁸ Work Programme Statistics (Updated 13 November, 2013):
<https://www.gov.uk/government/organisations/department-for-work-pensions/series/work-programme-statistics--2>

¹³⁹ Barnes, et al. 2011

¹⁴⁰ Adams et al., 2012

¹⁴¹ Post, et al., 2006

- 4) Support does not exist to genuinely encourage claimants who may often have been away from the labour market for some time; and
- 5) The system makes it either impossible or unreasonable for the claimant to take the risk of work.

Following extensive consultations receiving over 1,200 responses,¹⁴² sick and disabled people told us what work they might be able to do, what they would need to achieve their goals and how the system currently holds them back.

Broadly, 5 central themes came up time and time again.

- 1) Work needs to be totally flexible, available when and as the person is able to engage with it;
- 2) Working from home is easily achievable in the 21st century and many expressed a desire to work this way;
- 3) Training or further education could often help the sick or disabled person either find or stay in work but is often denied or patchy;
- 4) Developing hobbies or talents into small businesses would appeal to many, but the extra pressures involved in running a small business often make it impossible and the benefit system stifles progress;
- 5) Employers need to be engaged to a far higher degree whether through education, incentives, mandating or tax breaks.

Any out of work benefit carries the risk of being a disincentive to work unless it is flexible and tapers are set at the right level. Nevertheless, it is essential that there is some provision for those who cannot work in any genuinely self-supporting way. We have previously seen that the distinction between short term illness or disability, SSP and early intervention needs to be clearer, and much more needs to be done to keep those who suffer from short periods of incapacity in work.

However, many claimants have degenerative or fluctuating conditions that will always provide barriers to work. They may improve temporarily only to relapse at certain times, or they may only degenerate over time causing further barriers and complications. Conflating short term illness that will improve with those who will always be disabled by a long term condition is unhelpful.

Those with long term conditions may suffer from crippling fatigue, may have to use medications that interfere with their ability to drive or attend an office, and may suffer from pain or symptoms that are unpredictable. Traditional work support tends to either ignore these factors or deny them. Certainly the current structure of ESA makes these factors peripheral at best or even irrelevant. Instead, we argue that their consideration is central to achieving fulfilling, sustainable work activity.

¹⁴² 1. <http://diaryofabenefitscrounger.blogspot.co.uk/2011/05/welfare-for-people-by-people-continued.html>
2. <http://diaryofabenefitscrounger.blogspot.co.uk/2011/05/welfare-for-people-by-people.html>
3. <http://diaryofabenefitscrounger.blogspot.co.uk/2013/09/welfare-for-people-by-people-report.html>
4. <http://diaryofabenefitscrounger.blogspot.co.uk/2012/08/positive-experiences-of-back-to-work.html>

It is this cohort globally – this is far from a UK phenomenon alone – who pose the greatest challenges for the future. If we truly intend to aim for a social security system that functions as close to full employment as possible without causing suffering or harm, we must truly start to look at what support works, how best it can be delivered and the factors which commonly derail progress in achieving a fulfilling working life.

If you became unwell or disabled later in life, and have lived with a long term condition for some time, it is likely that you continued to work for as long as you possibly could, and usually longer than was healthy: even damaging recovery in some cases.¹⁴³ We have seen in previous sections that people themselves are usually the best judges of their own health and recovery, the best at identifying which work support or training might help them into sustainable work and best at realistically developing their own skills and talents in the way that suits them.¹⁴⁴

It is vital not to conflate this group with that frequently portrayed by politicians and the media as “scroungers” or “lazy”. We must start to change our core assumptions, moving from judgement to empowerment; from sanction to incentive; from intimidation to inspiration.

To truly change these attitudes will take considerable work, commitment and time. We currently do almost everything the wrong way around, and consider this cohort in entirely the wrong way. All recommendations below arise from, and are predicated upon, the need to ground this change at the heart of any future reform. Without such a change, they will fail as surely as other reforms have failed in the past.

Flexible Work and Home Working

By far the most common response to our consultations was people’s need for more opportunities to either work from home or to undertake some kind of work totally flexibly, at hours that suited them. Many commented that that might be at 2am when pain made sleeping difficult or for short bursts throughout the day, pacing their activity to best manage their symptoms and fatigue levels. Some might feel they would truly benefit from and enjoy work for a day or even more, but then would be unable to reliably work for days after. Many commented that they were unable to guarantee when those times might be and so work does not exist that they could do.

“I think one of the main problems with many illnesses is that you can't state categorically that on any given day you will be able to work. Employers don't like that. They also don't like it when you have to take several weeks off for surgery. With all the technology available today it should be easier to be able to work from home on the days you cannot get out of bed. If there were funding available for employers to set up home working for the disabled or sick and also a bank of temporary staff they could tap at a reasonable cost to cover times when you are in hospital or going through a really bad spell, I think they would be more willing to take on the financial

¹⁴³ See Gaffney, 2012

¹⁴⁴ See also DRUK, 2013

risk of employing someone who was disabled. Because until you level the playing field employers won't risk employing someone who in all likelihood will be unable to come into work every day. It simply will cost them too much. If an employer has a choice between someone who will probably make it into work most days and someone who probably won't make it into work at least 3-5 days a month, they are going to choose the healthy person, it's pure economics."

Traditional flexible working might involve part-time work, annualised hours (though this is often only available to existing employees) or job shares, but those solutions are unlikely to help people with the most severe long term or degenerative conditions who otherwise would like to do some kind of work. "Slivers of time" attempts to allow people to work as many or as few hours as they feel able, but in its present form gives little or no job security. Sick or disabled people above all need this security.

But the issue that truly compounds this inflexibility is the ability to do work that can be self-supporting. Many cannot ever hope to achieve enough working hours or a high enough salary to be reliably self-sufficient. At the moment, if a sick or disabled person takes a job, they often believe that they will lose all of their ESA. There are no tapered reductions. It may have taken them many months to make a successful claim, there is a new three month qualifying period if work fails, and they may be frightened of trying to work because of overly strict criteria or sanctions with no guarantee that they will be able to re-access ESA in the future.

"Making it easy to transfer in and out of work is an essential element I think. I've just found 4 weeks work, just above the ESA hours threshold...so I have to sign off and back on again. (not an easy task if you can't handle the phone)"

"It needs to be easier to move between in and out of work."

Everything about the current system disincentivises work, ignoring the existence of those who will genuinely always need a little extra support. Sick and disabled people often face marginal tax rates of over 100% as the amount of work they can do can never replace the ESA they lose.

Yet In fact, Permitted Work allows the person with a long term condition of disability to earn £101 per week for a 52 week period without putting their ESA in jeopardy. However, after one year, the amount falls to just £20 per week. The scheme is currently underused and not trusted. It is difficult to find data on how many people undertake permitted work. According to a recent freedom of information (FOI) request, "Information on permitted work status is collected on the Department's administrative data: however this information is not carried forward to the reporting datasets used for the routine publication of benefit statistics." This seems fairly remarkable in itself. However, the FOI goes on to say that "The raw benefit data indicate approximately 1.9% of ESA claimants have a permitted work start date."¹⁴⁵

¹⁴⁵ FOI request 48/2011 regarding the Permitted Work programme. Reply dated February 2011: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/221274/foi-48-2011-permitted-work.pdf

It seems extraordinary that this is not much more highly publicised and encouraged. As a way of transitioning into work, it counters many of the barriers that currently exist.

Universal Credit aims to improve incentives to work a little with more flexible, real time benefit adjustment, tapers into work and slightly more generous work allowances. However, these are still inadequate and still incur marginal tax rates of 65%.

“Although I would love to do a bit of paid work again, I wouldn’t do PW in the current climate. To be honest, I live in constant fear of losing my benefits, so I’m afraid of doing anything at all. Last year I was subjected to a farcical face-to-face assessment by a dishonest and ignorant Atos nurse who (among other things) refused to read my ESA50. I was found FFW on the most ridiculous grounds. I am now in the Support Group, but I’m paranoid about giving Atos/DWP an excuse to find me FFW again at my next assessment.”

Under Universal Credit, these factors are improved to a degree, but still leave high degrees of risk.

- **If you are single, claim housing costs and have a limited capability to work (LCW):** You may earn £192 per month (*Note: this is less than under Permitted Work*);
- **If you are single, don't claim housing costs and have LCW:** You may earn £647p/m;
- **If you have a partner, claim housing costs and one/both of you have LCW:** You may earn £192p/m (*This is also less than permitted work*);
- **If you have a partner, don't claim housing costs and one/both of you have LCW:** You may earn £647p/m.

After those amounts, any extra work would be subject to the 65% taper.

Recommendations:

- **Those with long term or degenerative conditions must be able to enter work with the lowest possible risks attached.**
- **They need to be reliably able to at least replace the ESA amount before they are worse off (i.e. tapers should only set in over the ESA amount of between £56.80 and £106.50 per week).**
- **They need a claim for support to be fluid – starting the moment work becomes impossible with no qualifying period. People need to be able to move easily between working and not working with as few risks associated as possible.**

Every Hour Counts

Every hour a person works should have a benefit, both to themselves and to the Treasury. **We propose a system where the client keeps 50% of anything they earn on top of their ESA. 25% would go to the treasury and the remaining 25% should go into a portable, personal fund that the sick or disabled person can take with them throughout their lifetime.**

We propose that this is “matched” by the government in the same way that pensions contributions are.

This fund could be used and controlled by the client themselves to pay for extra support at times when they are unable to work, to perhaps help employers find cover when work is impossible (perhaps during surgery or “flares” of a condition). It might help pay for rehab or extra treatment or iron out the ‘rollercoaster’ lifestyle of moving in and out of work.

“I was doing all right. I was seeing some recovery and doing a small amount of voluntary work but because I was naive enough to tell the nice ATOS lady they removed my benefit. This made me worse and I am now permanently under the care of the CMHT with the resources that uses.....I would have coped with them saying, ‘Do you think you could do two hours paid work a week? Here's an appointment with an enabler to help you do that, and we'll scale your benefit down as you get into work.’ In fact I wanted that to happen. Now I'm as much use as a chocolate fireguard to an employer and I've got to climb that recovery hill all over again.”

This type of scheme incorporates contribution, makes work pay and provides a buffer against uncertainty.

Flexible Work Agency

All businesses experience periods of higher activity where they need to take on temporary staff. Usually through agencies, this is an expensive and often unreliable way of using resources. Sick and disabled people often have a lifetime of experience that they can no longer use.

We propose a type of national, flexible work agency where sick and disabled people can be “interviewed” virtually and accepted as capable of taking on particular work. Businesses can offer short term or seasonal work they do not have the capacity for and sick and disabled people can log on at hours that suit them, to do as little or much work as they feel they can manage.

However, this work must not be simply menial, entry level and unskilled. This would ignore the vast wealth of experience on offer. Most work can be done remotely – paralegal, accountancy, marketing, sales, research, proof reading, peer review etc. It is vital that work on offer reflects the rich and varied skills and talents of those ready and willing to take it on. Employers should be engaged and encouraged to participate.

In the 21st century, it's surely time we took a much more innovative and imaginative approach to working from home and facilitating a virtual workforce.

Small businesses and local co-operatives

Many people responding to our consultations mentioned hobbies or activities they could extend or have attempted to extend into small businesses. People who are time rich but face physical challenges making it hard to work tend to look for productive, enjoyable ways of filling that time.

However, time and again, the same problems and fears came up. Starting a business is risky enough for those who enjoy full health, but a long term condition or disability can make it almost impossible. The client may be creative but have no “head for business”. They might make a wonderful product but be unable to get it to market. They may worry that they are unable to commit to filling orders in reasonable timescales or that their health may make it impossible to fulfil commitments to the customer. Finally, many reported being the victims of their own success, not failure. As soon as the business becomes viable, they lose their ESA and cannot sustain self-sufficiency.

“I've had several self-employed businesses before this one; the last was soap/body products and I broke even last year. However, it was hell - I have no car, very limited health and energy and even though I had return clients, more shows than I could even book into a week and plenty of fanbase, I had to stop running it. Again, this was NOT because the business wasn't successful – it's because it was becoming successful and I couldn't keep up. I didn't have enough to hire an employee but I desperately needed one; someone who could drive, handle accounts, send to fairs and trust with the money, and to wrap soaps or do packaging when I was having a really crap day.”

We propose a system of local co-operatives, designed to give the maximum support to any sick or disabled people considering self-employment.

“The other thing that often comes to mind is the possibility of a disabled workers co-operative working on things that they can take over from each other on one another's bad days.”

These could be staffed and controlled by disabled people themselves: some taking on marketing, some helping to get product to market. A system where local businesses run by sick and disabled people are linked up to provide support to one another and to fill in key skills that may not be available or viable.

“I have yet to understand why there isn't an effective "pairing" system between disabled people who may want to try and get a business off the ground. There needs to be a realisation that some of the only work many of us can do is at home, and self-employed disabled folk is better than nothing; with the appropriate software and a more able person to help with some of the stuff we might struggle with (accountancy, ordering, fine detail work, driving and business accounts, etc. etc.) it leaves us with the time and energy to do what we do have the energy to do - typing or dictation, craftwork, fixing computers, creating art.”

All local support should be available in one place with businesses advisors on hand to help negotiate the bewildering array of schemes and incentives.

Most small businesses take at least three years to start to see a profit, so we recommend that ESA should be reliable for at least this period before tapers set in unless a minimum agreed income is achieved and is judged to be sustainable at an earlier time.

In France, Business and Employment Co-operatives (BECs) help people to become self-employed in a range of activities through three stages of support. First, people remain technically unemployed but develop their business idea under the wing of the BEC. Next, if it looks like being a success, they become a “salaried entrepreneur” with the security of a part-time employment contract. Finally they become a self-sufficient business.¹⁴⁶ This kind of staged support offers a potentially viable model to support sick and disabled people attempting to start a business.

The government have recently extended Access to Work for those setting up their own businesses. This is welcome, but without all the other support working in tandem, this will not address all of the barriers that exist. What’s more, the Access to Work budget has fallen recently, and those applying report fewer small specialist providers. Needs are now often not being suitably met as these smaller providers are squeezed out of the market.

Only others with barriers to work or considerable experience of working with those with long term conditions can really understand the extra burdens and strains of trying to run a business and cope with an illness or disability. As such, co-production and support is a vital component of this recommendation.

Online Marketplaces & Mark of Excellence

Many respondents commented that the enormous reach of the internet now made it easier for people living with long term health conditions or disabilities to effectively get product to market.

With courier firms and online payment systems, some of the barriers to self-employment can be lifted through online marketing and sales.

Some suggested that there should be mark of excellence similar to the British Kite Mark that denoted products made by or for sick and disabled people of a high quality. A site that allowed those products and services to be showcased in one place was also suggested.

Education and training

All current evidence shows that education and training make the biggest difference to whether someone with an illness or disability can find or stay in work. Those with the highest levels of educational achievement are the most likely to be in work and for that work to offer self-sufficiency and decent levels of pay. Of course, this is true of most workers, but those with the greatest health or disability related barriers to work need the most to offer potential employers.

¹⁴⁶ See Casebourne & Coleman, 2012

There is no doubt that bias exists against employing people with illnesses or disabilities - even though the law officially restricts employers from discriminating in this way. As many have argued, there is a “residual bias” in the labour market against those with illnesses or disabilities that isn’t currently addressed.

“Why do we even have discrimination laws when they aren't being enforced? Not only for the disabled but for more mature workers as well? If the government can't at least crack down on these laws or be bothered to change employer's views on disabled people in the workplace, then maybe there should be more initiatives to help people start up their own business.”

“I was so sick of applying for jobs and not even getting an interview. I decided to try an experiment. I applied for 15 jobs where I mentioned my disability and 15 where I did not. I got no interviews at all for the first 15, but because of my experience, I got 13 interviews out of the other 15. To me, this proves there is discrimination, however much employers might deny it.”

Unlike the benefit system, the help available for those attempting to access further education or training is well thought of. Disabled Student Allowances (DSAs) are generally praised and users report a high level of support and provision or aids or adaptations through the scheme. Though users report it can be difficult to navigate the bureaucracy of the scheme and aids can often take a long time to come through, respondents reported none of the restrictions or judgemental approach they often experience in the benefit system. Respondents overwhelmingly reported that their advisor was very helpful, that they were offered a wide range of aids or adaptations to genuinely help them to study. They reported that there was a high level of understanding and that reasonable adjustments were often made to help with sitting exams, writing coursework or completing assignments. These included but were not restricted to

- 1) Extra time to sit exams;
- 2) Breaks during exams;
- 3) Software to help with reading or writing assignments;
- 4) Travel assistance; and
- 5) Studying from home (i.e. not required to attend physically)

The Open University also received almost universal approval. Similar points were made that the course tutors were willing to be extremely flexible, that reasonable adjustments were made wherever possible, including extending course deadlines, sending tutors and invigilators to the home wherever possible, and allowing extra time for exams with breaks where necessary.

Many universities offer limited places without fees for sick and disabled people and have dedicated staff available to make reasonable adjustments to enable full inclusion. This is little known and poorly advertised.

We recommend that the positive feedback from this section shows that making literature and advisors more available to sick and disabled people both in work and out of work would be very valuable.

Local “One Stop Shops” with information about further education or training should gather all relevant information in one place, with advisors able to help people navigate the system. (This is something the caseworker in ESA should be able to advise and support on along with benefits, health, work support and so on). Sick and disabled people should receive much more information about further education and training and, indeed, the portable work fund (see above) could be made available to cover any costs not taken care of by the DSAs or OU themselves. This information could routinely be sent out with social security letters and employers should be encouraged to have information easily available for workers struggling in their current roles.

If we aim for the highest levels of education and training possible amongst our sick and disabled community, there is no doubt that it would do more to improve the chance of self-sustaining work than almost anything else.

Employer Engagement

Many respondents said that not nearly enough had been done to engage business. There had been little attempt to explain why taking on those with long term conditions or disabilities could be of benefit to UK businesses. Only the negatives ever seemed to be discussed (time off work, lack of reliability, and so on) but studies show that many sick and disabled people who are employed are more loyal and more productive when they are in work than many without impairments.¹⁴⁷

“Why don’t the employers change their views on disabled people, after all we are more likely to be in work with a cold and flu than normal people.”

Respondents argued that much more could be done to sell the idea of a highly experienced (through often long and successful careers) and flexible workforce (able to work unusual or variable hours).

Many countries mandate or incentivise employers to employ a certain percentage of sick and disabled people whether through targets, quotas or tax incentives.

“Employers should be encouraged (through tax breaks or grant 'add-ons') to provide suitable working options for ill/disabled, carers and working parents – like job sharing and working from home. If people incur extras cost by being disabled they should be helped, if people need care they need care.”

“If there are over 2 million unemployed and over 1 million 'off the sick' why doesn't the government proclaim in law that for every 3 jobs you have open you MUST

¹⁴⁷ Carroll 2011, Parliamentary Briefing: Crohn's Disease

employ a disabled or chronically sick person. That's what they want, to 'support' us so where's the money to fund that for employers?"

"Since my husband was made redundant three years ago, he hasn't had any luck at all finding work. I think employers need to have more incentive to hire disabled people. I don't think all this stuff in the media portraying the sick and disabled as lazy, scrounging cheats has helped. What employer would want to hire someone like that?"

Inclusion London suggested that initially, this could be approached by ensuring that any companies bidding for government contracts should meet minimum quotas for employing and supporting sick and disabled people.¹⁴⁸

But it is crucial that this is not seen as merely a duty. For the future workforce to function fluidly and flexibly, most businesses accept and understand that they need to do more to encourage flexible working, job shares, home working and virtual workplaces. The technology exists, it is often more cost effective for businesses to employ people this way and there are fewer employer workplace responsibilities. Nearly all businesses experience times of peak activity where they do not have the staff resources to cover output. Suggestions like the Flexible Work Agency and increasing the educational standards of employees all serve business.

However, problems have arisen where adjustments serve only the employer not the employee. So "slivers of time" as currently suggested by the coalition often means zero hours contracts and no employee security. Working small amounts often results in the employee being worse off (and this won't necessarily change under Universal Credit). **It is crucial that any schemes to improve working opportunities for those with barriers through ill health or disability are made to work for the employee as well as the employer. This currently cannot be said to be the case.**

We recommend a genuine commitment to engage with employers and change the narrative on employing sick and disabled people. We believe that things will only truly improve if business can see that there is a strong and genuine commitment from government to engage and attempt to solve the problems which are currently excluding sick and disabled people from the workplace. Whilst this report focuses on difficulties from the perspective of the person with barriers to work, there is no doubt that more could be done to support employers willing to take on those with impairments. Access to Work can cover aids and adaptations but schemes to cover reasonable sick leave or to make it more financially viable to take on sick and disabled people must work in conjunctions with this.

"Employers are driven by cost and outcome goals so until it is made worthwhile for employers to employ those with disadvantages in either being reliable at turning up for most days and fully carrying out the required functions equal to a fit person they will by and large opt for the fit employee."

¹⁴⁸ Byrne, 2013

Childcare – Disabled Parents/Disabled Children

Many respondents pointed out that there was a severe lack of childcare available to support parents into work if the child had an illness, disability or learning disability. Similarly, however, disabled parents reported overwhelmingly that social services seemed to have no provision or guidelines on how to – or even whether to – support them in their parenting role. It is in fact the role of adult services to ensure that the sick or disabled parent is able to carry out their parenting role as fully as possible.¹⁴⁹ This might mean help with getting children to and from school, help to access the community with children and help in carrying out basic parenting tasks such as dressing or feeding small children.

In practise, respondents reported a never ending cycle of being passed from adult services to child services, to charities and back again in a never ending loop. Often, services simply didn't exist to provide the support or childcare needed.

“Childcare for special needs kids in my area:

After School: Nothing for over 12s exists in my locality for any child – mainstream childcare or special needs.

Holiday Childcare: one scheme exists but it is under-funded so no reliable places available- sometimes you get the number you ask for if you're willing to accept any day and are only after 2 days sometimes you are lucky if you can get anything at all (some weeks there is nothing) – if you request specific days (such as would be needed if you worked) you reduce your chances of getting anything so are unlikely to get your child in even once a week.

Funding is short term and charitable funding only so unreliable and it is surviving one holiday to the next under constant threat of closure due to lack of money.”

We recommend much more clarification and attention on this area of support.

- **Childcare places for children with disabilities need to be urgently increased.**
- **We suggest a framework guiding social services and other providers on best practise for parents with disabilities needs to be put in place and thoroughly integrated into local social services.**

Contribution

Much of the debate recently has focused on contribution. Yet still, overwhelmingly, politicians tend to think of this contribution in only financial terms.

Carers save the economy between £87 billion¹⁵⁰ and £119 billion¹⁵¹ a year, whilst voluntary work keeps the country functioning, safe and secure, often filling in gaps the state does not

¹⁴⁹ NHS: Help for disabled parents: <http://www.nhs.uk/Livewell/Disability/Pages/help-for-disabled-parents.aspx>

¹⁵⁰ Carers Trust: Carers save the UK economy £87 billion a year: <http://www.carers.org/news/carers-save-uk-economy-%C2%A387-billion-year>

cover. Yet these contributions are rarely recognised or appreciated. In fact, the system often makes caring or volunteering incredibly difficult. Many respondents stated that the current climate of fear and judgement makes people too scared to try even a little voluntary work, in case assessors take this as proof the person can manage full time, self-supporting work. The whole concept of work experience has been overwhelmingly skewed by so called “workfare” schemes. Carers are woefully unsupported with already inadequate respite services being cut and scaled back.

Any system that attempts to include a contributory element must include these contributions and recognise that they are equally as valuable as paid work.

“Most of us do worthwhile things in our lives, it's just that we're not paid for it. I help my local authority write leaflets for service users and I also organise the care for an older neighbour by holding her care budget in the bank account, paying the bills etc. These are worthwhile tasks which might be paid in another context but which I do unpaid.”

We recommend a “carer’s credit” and a “voluntary credit” that acknowledges this vast contribution, either by adding additional pension credits, reducing tax thresholds, or by extending access to the small “top up payments” outlined and explained previously.

¹⁵¹ Carers UK: Unpaid carers save £119 billion a year: <http://www.carersuk.org/newsroom/item/2121-unpaid-carers-save-%C2%A3119-billion-a-year>

Conclusion

This report shows very clearly that the status quo cannot continue.

Backlogs are increasing, assessment staff are demoralised, jobcentres are stretched to breaking point and work providers are pulling out of the Work Programme. Yet, for all this, the effect of reform on overall ESA numbers has been negligible.

Few of the changes recommended here could happen overnight and all will take real political will to achieve.

But however perfect any system we design could be, if attitudes don't change radically, then reform of any kind will fail.

We currently have a system which denies, restricts, judges and harms. No new descriptors or alternative schemes can address that. If we create a system designed only to catch cheats, we ignore the remaining 99.7% of sick and disabled people who urgently need access to the best possible solutions.¹⁵² Indeed, the current reforms have not only failed, but have often made the situation worse. Fewer sick and disabled people currently find work than under the previous system.

ESA and WCAs have become politically toxic. There is no question of continuing down this path if we truly intend to do the best we possibly can for those who can work whilst causing as little stress and suffering to those who cannot.

Instead we must be radical and ambitious. We must build a system hand in hand with the very people who will use it, while turning preconceived ideas of reform upside down.

Our intent must always be to inspire and facilitate, not to demean or restrict. We must move from sanction to incentive, from judgement to trust, from fear to aspiration. We must treat people as individuals, not numbers on a balance sheet. We must realise that sick and disabled people are the victims of social security fraud, not the perpetrators. And we must accept that people overwhelmingly tend to do their best, try as hard as they are able, and continually strive to achieve their full potential. This is currently very far from the case.

In business, a good manager is often able to inspire their workforce, to get the very best from them they can. In contrast, a bad manager is one who institutes a climate of fear and resentment. As managers of an advanced, compassionate democracy, it is time we embraced a new understanding of the link between sickness, disability and work. The international evidence is clear: where systems are based on encouragement, respect and individual support, outcomes are better. Job starts are more sustained. Fraud remains low.

A system that works for sick and disabled people, while also creating value for taxpayers, need not be a contradiction in terms. But to achieve it, we must first be prepared to listen.

¹⁵² The preliminary estimated rate of fraud for IB in 2012/13 is just 0.3%. See DWP, 2013e.

Appendix A – Incapacity Prevalence

The design of ESA was originally based on the assumption that around 1 million people who were claiming the old Incapacity Benefit (IB) should not be doing so.

This is based in turn on two assumptions. One is on the assumption that IB is accessible to people who can work, but face minor disadvantage at a time of relatively low employment. I.e. it is assumed that the qualifying criteria for IB is so low as to mean that people who are not truly incapacitated can claim benefit on the basis of incapacitation.

The other is that the increase in claims between 1971 (when Invalidity Benefit [IVB] was introduced) and 1995 (when it was replaced with IB) is ‘inexplicable.’ It is assumed that too many people claimed IB given the level of ill-health in the country. Because ill-health has not dramatically increased since 1971, therefore, it is claimed that inappropriate access must be behind the rise in the rate of claims.

However, this ignores the key question: what is the expected level of incapacity in this country? ESA policy assumes that the ‘correct’ level is around 1.5 million; so 1 million more than 1971 but 1 million less than 1995. However, there is no evidence to suggest that 1.5 million is any more appropriate than 0.5 million or 2.5 million.

Given the many questions already addressed about the efficacy of ESA in its current form, it is vital that there is thorough consideration to the question of how many people in the UK are in fact incapacitated for work.

This is difficult to assess. It assumes that someone can accurately and objectively tell whether another person is incapacitated. It has been suggested that people self-justify and over-dramatise, but again, there is no evidence to back this up.

People can self-assess accurately, and on a comparable level to a doctor. People do not return to work just because they are told they are well enough. They return because they recover.

Further research is being conducted to explore what happens to people who try to work before they are ready. This will feed in to this debate.

The fundamental question we will attempt to answer here is: how many people in the UK are incapacitated: or, to put it another way, what is the prevalence of incapacity in the UK?

The answers come from the available disability surveys. These are:

Survey	Question	Prevalence	Year
Family Resources Survey	Disabled	16.2%	2011
	... and Not in Work	8.8%	
	... and Inactive	8%	

	... and Permanently Disabled	6.1%	
General Household (Lifestyle) Survey	Long-term illness	32%	2011
	Limiting Long-term illness	18.5%	
	... and Not in Work	8.7%	
	... and Inactive	7.8%	
Labour Force Survey	All Limited	18.7%	2009
	... and Not in Work	9.4%	
	... and Inactive	8.3%	
	Limited in day-to-day	15.8%	
	... and Not in Work	8.4%	
	... and Inactive	7.6%	
	Limited in work	14.0%	
	... and Not in Work	8.5%	
	... and Inactive	7.5%	
Life Opportunities Survey	Impaired	23.2%	2009
	... and Not in Work	10.4%	
	... and Inactive	8.8%	
	... and Inactive because sick, disabled or retired	6.3%	
	... and Inactive because sick or disabled	5.3%	
	EA disabled	18.8%	
	... and Not in Work	9.6%	
	... and Inactive	8.3%	
	... and Inactive because sick, disabled or retired	6.2%	
... and Inactive because sick or disabled	5.5%		

Comparisons

The Family Resources Survey and Life Opportunities Survey use responses to questions on barriers to assess disability. They may therefore be considered more objective.

The General Household Survey and Labour Force Survey ask for self-assessment on limitations.

The data from the FRS and GHS are on men and women aged 16-64. The LFS used the old definition where women aged 60-64 are excluded. The LOS data could be used to give overall prevalence for people aged 16-64 but the prevalence linked to worklessness was based on the old definition of working age. This, along with the LFS data, therefore underestimates the prevalence of working-aged disability. Conversely, the other data sets do not separate inactivity by reason; there may be people who are limited, impaired or disabled and inactive, but who do not face such labour market disadvantage as to merit an incapacity benefit.

Results

Estimates of disability combined with economic inactivity range from 5.3% to 8.8%. 5.5% is likely to be an underestimate for methodological reasons – it excludes women aged 60-64; and it considers only those who are inactive through ‘sickness or disability’ and not through

retirement, where it might reasonably be expected that people with a disability or impairment who have retired early may have done so for health reasons.

The median prevalence of incapacity in the surveys is 8.3%, with 6.9% as the lower quartile and 8.75% as the upper quartile.

Discussion

Incapacity prevalence in the UK is therefore likely to be between 6.9% and 8.75%. This is between 2.7 and 3.7 million people, based on the current working age population.

The current incapacity benefit caseload is just under 2.5 million, or 6.1% of the working age population. This is below the inter-quartile range. It is equal to the third lowest estimate, which is for 'Permanently Disabled people' in the Family Resources Survey. The two lower estimates are both from the Life Opportunities Survey and are likely to be under-estimates.

Health Trends

The prevalence of incapacity is unlikely to have changed since incapacity benefits were first introduced. Whilst overall health improved, the health of those who were most ill or living in deprived areas has not improved. However, the issue at stake is not how the average health has improved but how the health of those at the bottom – those who qualify or almost qualify for incapacity benefits – has changed. Like the 2013 recovery from recession, it may be that it is only the already better-off groups that are experiencing improvement whilst others decline or remain stable.

A 1997 paper found that the most deprived areas in the UK had not seen an increase in life expectancy compared to the early 1970s, and had in fact seen a decline in survival rates for young adults (20-29).¹⁵³ A more recent paper found that not only do more deprived areas show less improvement in mortality, but that areas of mining, manufacturing and industry have even lower life expectancies than predicted given their level of deprivation.¹⁵⁴ The trends from the surveys also indicate a lack of change in the health of the most disabled.

Accessibility of Benefits

Until 1995, when the Incapacity Benefit caseload first reached 2.5 million, the caseload did not match the expected numbers of eligible people. It is therefore reasonable to assume that the increase between 1971 and 1995 represents the caseload catching up with the level it should always have been at. It is unlikely to be because of over-lax access rules.

Indeed, a study in 1998 by the DWP concluded that assumptions that “a significant proportion were people capable of work and should not, therefore, be receiving incapacity benefits” and of “an excessive ease with which some people appeared to be able to claim Invalidity Benefit” were unfounded. Invalidity Benefit, therefore, was not overly-accessible.

¹⁵³ Raleigh & Kiri, 1997

¹⁵⁴ Doran, et al., 2006

Neither was Incapacity Benefit – the OECD in 2006 considered that IB was one of the harshest tests amongst OECD countries. In comparison, ESA is well-known to be an even harsher test, and indeed was explicitly designed to be so – with the aim of removing the alleged 1 million recipients who, it was assumed, were claiming the benefit too easily compared to previous IB figures.

Individual attitudes

Nor do changing attitudes explain the increase in IB recipients. It has been suggested that people over-rate their disability when out of work, and particularly when told they are incapable of work. If this were true, there would be more people claiming incapacity benefits during a recession. This however is not what is seen; incapacity benefit numbers have not varied in sync with recessions.

The argument is also made that there are not more people who are incapacitated, but more people who view themselves as incapacitated (even though not truly so). If this were so, we might expect a greater increase, or variation in sync with recessions, for people reporting less severe conditions than for more severe cases. This is not seen: self-reporting of more severe conditions has increased at the same rate as less severe, and neither are in sync with recessions.

Other evidence suggests that people's self-perception of their level of disability tends to be accurate; for example, they are often better able to predict the duration of their incapacity than their doctors. When people leave incapacity benefits voluntarily, a much higher proportion enter work than if they were disallowed the benefit. Of those who enter work, a higher proportion of those who were disallowed Incapacity Benefit subsequently have to leave work for health reasons and re-join Incapacity Benefit than do those who voluntarily left IB.

That people who voluntarily leave, do later have to re-join incapacity benefit or sign-off sick suggests that some people are more likely to under- rather than over-state their level of disability. Employees who have had more than one sickness absence relating to the same condition take longer to return to work, compared to when sickness absence is due to different conditions.

The explanation put forward by Post et al is that "Possibly these employees were not fully recovered after the earlier sickness absence spells or were subjected to the same functional demands of the work while not being able to meet these demands, and thus had to report ill again." Studies of people with mental health issues suggest that many try to return to work too soon, and advisers have to be careful to prevent this.

Equally, where leaving Incapacity benefits was involuntary, there is little indication that these people adjust their self-perception to fit with the judgment that they are capable of work. In a follow-up study of people disallowed Incapacity Benefit, 35% had returned to IB within five to ten months of being disallowed, and with only 21% doing work of at least 16 hours a week, the rest had to rely on other income such as from a spouse or pension. 19% of those who had initially tried paid work had had to return to sickness benefit (i.e., became

unemployed and not looking for work due to poor health). Only 4% said they had fully recovered; 41% rated themselves as the same, whilst 31% had got worse since being refused benefit. Other studies in America found that tightening access to incapacity benefits did not result in sustained returns to work, as people disallowed would re-apply within a few years.

Beatty et al find that ‘ill health or injury was a factor cited in male ICB claimants’ last job ending “in *only three-quarters of cases overall.*” However, given the link between unemployment (or, perhaps more directly, low income) and poor health, it is feasible that people who lose their job for reasons other than health subsequently go on to develop a health condition that renders them incapable of work. Given other evidence, this explanation fits better than a hypothesis that these people view their health as a barrier mainly because they were told it is so by an incapacity assessment, as opposed to their own experience of their health accurately informing them of their ability to work.

Truly sick?

An analysis by Steve Griffiths shows that whilst unemployment rates do correlate with health measures, the correlation between Incapacity Benefit claims and health is even stronger. This suggests that the health of people on incapacity benefit is lower than the health of other unemployed people. Figures for ESA show that the death rate for people in the Work-Related Activity Group or waiting for a decision is more than double the working-age death rate, whilst those in the Support Group have almost 30 times the standard death rate.¹⁵⁵

	WRAG	SG	Assessment	Working-age
Man years lived	264 344	112 069	418 497	100 000
deaths	1300	7100	2200	225
death rate	0.0049	0.0634	0.0053	0.00225
deaths per 100k	492	6335	526	225
relative to standard death rate	2.19	28.16	2.34	1

An analysis done for the DWP on what happens to those leaving IB showed that the majority still had health-related barriers to employment that affected the type and/or amount of work that they could do; the majority was even greater when considering only those who had been disallowed rather than including voluntary leavers. The research report concluded “nearly everyone had the impression that they had left benefit with a continuing disadvantage in the labour market that was traceable to their disability.” **12-18 months after being disallowed IB, only 23% were in work of at least 16 hours. Over a third returned to IB within ... yersx`.** Of those who had recovered, this was almost entirely those who had voluntarily left IB or had decided not to appeal.

Of those on IB, 59% say their condition limits them ‘a great deal.’ “Health problems were the most frequently mentioned barrier to finding, and staying in, work and most frequently

¹⁵⁵ ONS, 2012; DWP, 2012

the cause of work ending.” A self-assessed improvement in health was associated with a greater proportion being in paid work: 83% of those who said they had made a full recovery were in work after leaving IB.

Beatty and Fothergill 2004 suggest that IB is easily accessed: “In practice, however, the tests applied by the Benefits Agency assess ability to undertake certain basic physical tasks rather than inability to do all kinds of work in all circumstances. Many unemployed people have picked up injuries over the course of their working life, and there is the effect on health and physical abilities of simply getting older. In practice, therefore, many of the unemployed with health problems are able to claim IB rather than JSA.” (Beatty & Fothergill, 2004).

In contrast, the OECD explained the UK’s high off-flow as due in part to “a reasonably rigorous medical testing regime,” which they also cited as the reason why the 1980-1995 increase reversed after 1995 (OECD, 2003).

This is also the experience of disabled people. Incapacity Benefit was not felt to be an accessible benefit. Assessments were described as rushed, pressured, incomplete and insensitive. It was particularly bad for people with mental health problems or learning difficulties (Citizen's Advice Bureaux, 2006). **The appeal volume and success rate was so bad that in 2005 Judge Harris complained that, “The themes in the ... reports have remained the same ... There seems little point in my colleagues and I providing more feedback or the Department commissioning further studies from the Appeals Service or their own Standards Committee when no discernible improvement in decision-making is the result. (Appeals Service, 2005)”**

Conclusion

Since 1995, the Incapacity Benefit caseload has remained relatively stable. However in 2008 the new ESA was introduced with much stricter criteria and with the expectation of removing 1 million people from the caseload. This research shows that the core assumptions underlying this change are far from proven, and that the burden of evidence indicates that this policy goal in fact works only to deny those affected access to a benefit appropriate for that disability status. **ESA should be revoked and replaced with a benefit that correctly identifies all of those who qualify.**

Methods of Surveys

The **Family Resources Survey** counts those who have “a long-standing illness, disability or impairment which causes substantial difficulty with day-to-day activities. Everyone classified as disabled under this definition would also be classified as disabled under the general definition of disability in the Equality Act (EA) which has applied since 1 October 2010. However, some individuals classified as disabled and having rights under the EA would not be captured by this definition.”

Individuals are assessed as disabled based on their response to questions on barriers across nine areas of life (in 2002/03 and 2003/04 there were eight areas used).

The survey gives the prevalence of disability by age, in bands of 5 years, and by gender. This allows the working-age prevalence to be calculated based on the old definition of working-age (for men 16-64 and women 16-59) as well as on the new definition of all people aged 16-64. The old definition gives a disability prevalence of 15.5% compared to 16.2% under the new definition. The old definition, as expected, under-estimates the disability prevalence by excluding older women (aged 60-64).

The **General Household Survey**: People are asked if they have a long-standing illness or disability; and if this illness or disability limits their activities. The data is presented split by age, with 16-44 and 45-64 bands covering the working-age population. This was averaged to give the prevalence of longstanding and limiting longstanding illness or disability in the working-age population.

The GHS survey gave the percentage of working (11.75), unemployed (26.5) and inactive (36.75) people reporting limiting long-standing illness or disability. However it did not give the numbers of people of working age who were working, unemployed or inactive so this data was taken from the Labour Force Survey.

This data was combined to give the prevalence of LLTI and worklessness, and LLTI and Inactivity in the working-age population. However these estimates will be affected by the LFS including women only up to the age 59, whereas the GHS covered women up to 64.

The **Labour Force Survey** is for men aged 16-64 and women aged 16-59. People are asked if their general health is very good, good, fair, bad or very bad; if they have a health condition expected to last for more than a year that limits the type or amount of work they might do; and whether this health condition limits their ability to carry out normal day-to-day activities. This is cross-referenced in the survey data with their economic status (employed, unemployed or inactive).

The percentage workless was multiplied by the percentage disabled to give the prevalence of workless disabled people in the working-age population. As impairment prevalence increases with age it is reasonable to expect that worklessness combined with disability would also increase with age. Because women aged 60-64 were excluded from this data, it is likely that the prevalence of worklessness combined with disability is underestimated.

The **Life Opportunities Survey**: A person was defined as impaired if:

- “they experience either moderate, severe or complete difficulty within at least one area of physical or mental functioning,” and
- “certain activities are limited in any way as a result. ‘Activities’ refer to different areas of physical or mental functioning, such as walking, climbing stairs or reading a newspaper.”

The survey gave breakdown of impairment prevalence by age, in bands of 5 years from 16 to 85+. This was averaged to give a prevalence for those aged 16-64 of 23.2%.

A person was disabled as defined by the Equality Act 2010 if they have a “mental or physical impairment that has a substantial and long-term adverse effect on the person’s ability to carry out normal day-to-day activities.”

The survey gave breakdown of Equality Act Disability prevalence by age, in bands of 5 years from 16 to 85+. This was averaged to give a prevalence for those aged 16-64 and with a disability as defined by the Equality Act of 18.8%.

The survey gave breakdown of economic activity status by impairment status and by EA disability status. Economic activity was given for men aged 16-64 and women aged 16-59. As impairment prevalence increases with age it is reasonable to expect that inactivity, unemployment or retirement due to health would also increase with age. Because women aged 60-64 were excluded from this data, it is likely that the prevalence of worklessness for health reasons is underestimated.

Multiplying the worklessness rate by the disability prevalence rate gave the prevalence of worklessness for health reasons in the working-age population. Different estimates of health-related worklessness were used, as shown in Table 1.

It would have been useful to have been able to examine for each survey how trends in disability varied since 1971, but this data was not obtainable.

The **Family Resources Survey** of 2010/11 (the earliest obtainable report) contained a graph of disability prevalence. This had been static at around 15% since 2002/03. It is regrettable that earlier data and exact readings were not obtainable. However, as the methodology for assessing disability changed in 2002/03 from previous years, this would have helped only as a general indicator against other surveys.

The **General Health Survey** of 2011 reported that “the proportion of people reporting a limiting long-standing illness or disability has changed very little since it was first asked on the survey in 1975: the proportion of people reporting a limiting longstanding illness or disability in 1975 was 15% and in 2011 this proportion was 19%.” This is in fact a four percentage point difference and almost a 25% increase.

The same report says there was an increase in long-standing illness or disability between 1972 and 1991. This is not relevant to this study as it includes people who report no limitation. The increase was attributed to “the increase in life expectancy and decrease in family size which has resulted in a much higher proportion of individuals in older age groups where long-standing illness or disability is likely to be more common.”

Berthoud (2011) reported that, for people aged 20-59, the prevalence of limiting long-standing illness rose from 14% in 1975 to 18% in 1996, and then fell to 16% in 2004.

The **Labour Force Survey** is the most relevant survey as this focusses on working-age adults. Data from 1998 onwards is obtainable. This suggests that work incapacity prevalence, as measured above, has decreased by about 10%, or between 0.5 and 1.24 percentage points.

The **Life Opportunities Survey** has been in existence since 2009 only, so has no trends.

The **Health Survey for England** has been running since 1991. Data from 1993 onwards shows a slight increase in the proportion reporting bad or very bad health, from 5% to 7%. This is an increase of two percentage points; however the use of one significant figure suggests the likelihood of rounding errors. The increase might be as small as from 5.49% to 6.49%, or as large as from 4.49% to 7.49%.

The overall **trend** depends on the survey used. The FRS is static; the GHS and HSE report an increase; and the LFS reports a decrease. An assumption of no change may therefore be suitable when considering work incapacity prevalence.

Appendix B: “Work is the Best Form of Welfare” – A Critique Of Waddell and Burton (2006)

Waddell and Burton argue that “There are economic, social and moral arguments that, for those able to work, ‘work is the best form of welfare’.”¹⁵⁶

There are major provisos to this statement, not least the phrase ‘those able to work.’ This is not about those who can’t work. It is almost tautological: if work is not actively bad for you, then it is probably good for you.

A major criticism of extrapolating ‘work is good for you’ to all people is that the majority of studies are based on the unemployed generally, or on those with minor health conditions who are “essentially whole,” in the words of Waddell and Burton (2006). There is a lack of direct information on the effects of work for people with significant health problems, but various other findings can provide inferences for this group.

There is decent evidence that work can be bad for some people. GPs recognise, for example, that if someone turns up at their surgery with depression then some time off work can be powerfully therapeutic, not least because many people do not go to their GP until their depression is so severe as to be impacting their work.¹⁵⁷

Whilst the therapeutic benefits of work were not denied, the therapeutic benefits of NOT working were considered equally important. Where employees have repeated sick leave related to the same condition, it is possible that this occurs because time away from work promotes improvement whilst time in work leads to a further deterioration in health.¹⁵⁸ This is further supported by evidence that sickness presenteeism, i.e. attending work whilst sick, predicts future sick leave and future poor health.¹⁵⁹

It is ambiguous whether returning to work results in an improvement in symptoms. Various studies and systematic reviews return conflicting results,¹⁶⁰ and even where there is correlation the causal relationship is unclear with a risk of health selection (i.e., the people who return to work are those who had an improvement in symptoms prior to the return).¹⁶¹

When people return to work after time on incapacity benefit, 80% say that improvement in health was an important factor, and this supports the hypothesis of a health-selection effect.¹⁶²

A job of poor psychosocial quality can be worse than being unemployed. People in such a job experience greater decline in health, and people moving from unemployment to poor

¹⁵⁶ Waddell & Burton, 2006

¹⁵⁷ MacDonald, et al., 2012

¹⁵⁸ Post, et al., 2006

¹⁵⁹ Bergstrom, et al., 2009

¹⁶⁰ Crowther, et al., 2001

¹⁶¹ Marwaha & Johnson, 2004

¹⁶² Kemp & Davidson, 2008

quality jobs experience a decline in mental health.¹⁶³ Job insecurity and strain also have negative impacts on health¹⁶⁴ and this is particularly concerning as the effects are not attenuated for high-status roles.¹⁶⁵

It is possible that any negative effects of unemployment are not due to unemployment itself, but to other factors associated with unemployment. Jahoda (1984) argued that people “have deep seated needs for structuring their time use and perspective, for enlarging their social horizon, for participating in collective enterprises were they can feel useful, for knowing they have a recognized place in society, and for being active.” These are termed latent functions, and loss of these functions can have as big or bigger impact on mental health than loss of income (the manifest function of employment).¹⁶⁶

These functions can be obtained through means other than employment; social support, for example, helps to mediate the negative effects of unemployment,¹⁶⁷ whilst access to a stable, adequate income might be expected to mitigate the effects of financial poverty and insecurity.¹⁶⁸

The overall evidence suggests that one should be very cautious in advocating work as a ‘cure’ for ill-health. A range of factors inter-play that can make unemployment less ‘unhealthy’ and employment more so, even for those people who are in general in good health. For people with long-term or severe conditions, work can pose health risks and emphasising sickness presenteeism may serve to make health worse, not better.

¹⁶³ Butterworth, et al., 2011

¹⁶⁴ László, et al., 2010; D'Souza, et al., 2005

¹⁶⁵ D'Souza, et al., *ibid.*

¹⁶⁶ Creed & MacIntyre, 2001; Paul, et al., 2009

¹⁶⁷ Roberts, et al., 1997; Kroll & Lampert, 2011

¹⁶⁸ Paul & Moser, 2009

Appendix C: Further Analysis on the progress of Harrington year 1 Recommendations

Recommendation 1.

Harrington's recommendation:

The review recommends that Jobcentre Plus manages and supports the claimant during the course of their benefit claim and identifies their chosen healthcare adviser.

Government response:

Accept

The government will increase support for claimants by:

1. DWP staff telephoning the claimant
 - a. At the beginning of the claim to
 - i. Explain the Work Capability Assessment;
 - ii. Explain the claimant's responsibilities;
 - iii. "Stress ... the importance of:
 1. Fully completing the ESA50 questionnaire,
 2. Identifying [the] chosen healthcare provider,
 3. Providing additional evidence;"
 - iv. Explain "the support that is available after the Work Capability Assessment;" and
 - v. "Allay fears about the process."
 - b. At the outcome of the claim to explain:
 - i. The outcome of the assessment;
 - ii. Reasons for the decisions;
 - iii. Options for providing further evidence; and
 - iv. What will happen next, including:
 1. Information about Jobseeker's Allowance for those found fit for work; and
 2. Routeing "those who need to be in the Support Group to that group as soon as possible."¹⁶⁹

Evidence of application or success:

Respondents to the call for evidence for the year 3 Review – evidence gathered in summer 2012 - largely felt that support from the Jobcentre had not improved. The Disability Benefits Consortium carried out a survey which they submitted to the DWP as their response to the call for evidence.¹⁷⁰ The survey results showed a lack of improvement in support from the DWP and Jobcentre:

- "Over 75% of respondents disagreed (or strongly disagreed) that support from Jobcentre Plus had improved over the last 18 months" – this is suggestive that the government has either not increased support or, if it has done so, the changes have not had significant effect

¹⁶⁹ p.33 <http://www.dwp.gov.uk/docs/wca-review-2010.pdf>

¹⁷⁰ DBC 2012 Quotes in italics are from the DWP call for evidence.

- “Over 80% disagreed that “customers feel better informed about what to expect and what their responsibilities are.”” – [see a.i & a.ii for the government action to which this refers].
- “Almost 80% disagreed that “customers are more aware of the need to collect evidence from their favoured healthcare professional.”” – [see a.iii.3 & b.iii].
- Over 90% disagreed that “customers know more about the financial and back-to-work support available to them, dependent on the result of their application for ESA.”” – [see a.iv & b.iv].
- “Almost 75% disagreed that “customers who need to go straight into the support group are being directed there more effectively.”” – [see b.iv.2].
- “Over 85% agreed that “people are increasingly struggling to access support and advice to help them claim benefits.”” – [see a.iv & b.iv.1].
- “Almost 90% agreed that “increasing numbers of people are being left without adequate support by the welfare system.”” – [see a.iv & b.iv.1].

Replies to the Disability Benefits Consortium survey show that the welfare system is continuing to offer very low support, with inadequate information given to the claimants. The following responses are based on experience of ESA during the 18 months preceding the call for evidence:

- “Over 80% disagreed that “people are being effectively supported back (or into) work.”” – [see a.iv & b.iv.1].
- “Almost 75% disagreed that “people's health is likely to improve as a result of support provided by the welfare system.”” – [see a.iv & b.iv.1].
- “Just 12% of claimants were signposted to relevant organisations who might support them when going through an appeal.”

Overall, the percentage of claimants who had received an explanation of the decision and what it means to them remains low.

- Over 75% said that no-one had explained how or why a decision had been reached – [see b.i & b.ii].
- 77% said no-one had “explained what the decision meant for them.” (75% after April 2011) – [see b.i, b.ii & b.iv].

There was some slight difference between those who had been assessed before April 2011 and those who had been assessed afterwards, with those in the later group having slightly more positive experiences:

- Those who had received an explanation of the decision increased from 22% before April 2011 to 25% after April 2011.
- Those who had an explanation of what the decision meant for them had increased from 29% to 35%.

It therefore does not appear that support is adequate or that it has improved.

In terms of phone calls, it appears that these now occur *after* the WCA but not before. Support before the WCA is presumably now considered to be adequately covered by the ESA35/35A. A new form of this letter has been drafted and trialled to improve understanding and increase ESA50 returns.

The year three Review indicates that “Decision Makers now contact the claimant by telephone following the outcome of the WCA.” However, “Disappointingly many claimants reported that they had not received a call from the Department but would welcome such support. Nationally, approximately one in three calls get through to the claimant. This remains a concern and further efforts are needed to ensure as many claimants as possible receive the necessary help and support they need through the process.”

There is great variation across the country. According to the Review, much of the variation in success rate is “down to the attitude of local managers towards the increased workload on Decision Makers and the inevitable slowing in the number of claimants handled in a week.”

These phone calls can be “demanding” for Decision Makers, as “claimants can be upset, aggressive or totally shocked.” Benefit centres where these calls have been in place for longest “have come through to the other side, so to speak.” It is to be hoped that Decision Makers do not find this to have long-term consequences on stress levels.

The DWP has trialled a system whereby text messages are sent to the claimant prior to the call. This “improved the success rate of the calls” and these trials are to be extended.

Contact remained difficult for claimants by the time of the year three review, as “some people, particularly those with mental health conditions, stated that there was too much contact and they found this stressful and could exacerbate their existing condition. Other respondents stated that there had been none or little contact from DWP – despite the recommendations from the year one Review – and were often unaware what stage their claim was at.”

Overall, none of the changes put in place have had a noticeable effect on the assessment process. The evidence suggests that Jobcentre Plus is either not effectively, or not at all, managing and supporting the claimant during the course of their benefit claim. There is no evidence to suggest that claimants are being encouraged to name a healthcare provider. The data from the DBC survey suggests a lack of information given during the phone call, as whilst 35% agreed that they received an explanation of what their decision meant for them, fewer than 25% agreed that they had received an explanation of the decision. It would be useful to know how this group broke down as regards phone calls from Decision Makers versus other sources of information.

Conclusion:

Partially implemented with limited success.

The Jobcentre Plus does not successfully manage (phone calls do not occur before the WCA) or support (support is limited) the claimant during the claim process.

No mention has been made of Jobcentre Plus identifying the claimant’s healthcare professional.

Decisions Makers call claimants *after* their WCA. Only 1 in 3 of these calls get through.

Recommendation 2

Harrington's recommendation:

The review recommends that the initial questionnaire (the ESA50) includes a more personalised justification so the claimant can express the issues that they face in a short paragraph.

Government response:

Accept.

Evidence of application or success:

The ESA50 now contains a page with a text box to explain "what is your disability, illness or condition, and how does it affect you?" Although the box itself has been reduced in size in the latest version of the ESA50, the questionnaire encourages people to use extra space if needed.

Conclusion:

Implemented.

Recommendation 3

Harrington's recommendation:

In the longer term, the review recommends that the Government reviews the ESA50 to ensure it is the most effective tool for capturing relevant information about the claimant.

Government response:

Accept

The government "will continue to keep the ESA50 questionnaire under review to ensure that it captures the most relevant information to support Decision Makers in making accurate decisions." In response to this recommendation and to recommendation 2 (above), the government has added a text box for claimants to explain how their condition affects them. The government aims to make the ESA50 form "more user-friendly."

Evidence of application or success:

The government say that the ESA50 form has been under constant review. However, it does not seem that the changes to the ESA50 form have made it "more user-friendly."

- Almost 8 in 10 (79%) of DBC respondents to the 2012 survey found the application form 'hard' or 'very hard' to complete.
- The form has been described as lengthy, repetitive, ambiguous and tricky. Claimants report that completing the form can take many hours, spread over multiple days.

It is worth noting that any questionnaire designed to capture most of a wide variety of illnesses and abilities will almost certainly have to be long.

Claimants felt that the ESA does not capture "the most relevant information to support Decision Makers in making accurate decisions." According to the DBC report, "Many claimants commented that the form did not ask questions relevant to their life and condition (particularly those with mental health or fluctuating conditions), or that they found the form confusing, too long and repetitive." Comments include:

- “Not relevant questions and not enough scope within tick boxes to answer efficiently when talking about long term condition fluctuations.”
- “Very ambiguous and tricky as though they were trying to catch you out.”
- “It did not appear to acknowledge mental health as a health condition.”

The year three Review itself reported that, “A consistent response [to the third year call for evidence] was that the ESA50 is too complicated and does not have enough space for the claimant to explain fully how their condition affects them on a daily basis.”

By the third year, the Review was able to say that, “the fluctuating conditions group have produced what the Review considers to be an excellent set of proposals to improve the initial ESA50 form which the Reviewer commended to DWP. Work to update the ESA50 is progressing and should be completed early in 2013.” It will be interesting to see if this new form is considered to be an improvement on the previous.

Conclusion:

Implemented with limited success.

Claimants continue to feel that the ESA50 is not an “effective tool for capturing relevant information.”

Recommendation 4

Harrington’s Recommendation:

The Review recommends that written communications to the claimant are comprehensively reviewed so that they are clearer, less threatening, contain less jargon and fully explain the process.

Government’s Response:

Accept

Revised IB reassessment notifications will be issued from early 2011.

Evidence of application or success:

The Review’s first-year recommendation included decision notifications, those sent “at the beginning of the claim,” and those sent “as they [claimants] book their Atos assessment.” Harrington specifically identifies the phrases, “your benefit may be affected” and “we may stop your benefit” as being potential causes of anxiety or confusion.

He considers that “large volume of communications that are sent to claimants do not as a whole add up to a coherent and easily understandable explanation of the process.”

He continues with concerns regarding advice on the ESA50 form: “For example, the guidance on completing the ESA50 tends to focus on what claimants should enter but does not explain how the information that claimants provide will be used.”

The year two Review said that, “The follow-up letters have also been made clearer and less threatening.” The government’s response to this review included the statement, “communications have been overhauled so the process is now more empathetic,” and “DWP Operations has also reviewed the key written communications sent to claimants to ensure they are clear, accessible and do not contain jargon.” However, the DBC’s response

to the year two Call for Evidence showed that most claimants and welfare advisers did not consider that written communications had improved since early 2011.

In the third review, Prof. Harrington says that the DWP “sought views from claimants in the last eleven months” and these views indicate that the ESA35/35A “provides claimants with clearer information about the WCA and the next steps.”

The DBC concluded in its response to the third year call for evidence that, “Communications have improved to some extent – letters appear to be clearer ... however the majority of responses regarding communications remained negative.”

Conclusion:

Partially implemented with limited success.

The government has not addressed issues regarding advice provided with the ESA50 form. Written communication may now be clearer, but there is little evidence from claimants or welfare advisers on whether this is the case, or on whether communication is now less threatening and more empathetic.

Recommendation 5

Harrington’s Recommendation:

The review recommends that every Atos assessment contains a personalised summary of the assessment in plain English.

Government’s Response:

Accept

We agree that it is crucial that all ESA reports clearly convey the basis of the healthcare professional's opinion on capability for work. All Atos healthcare professionals will receive updated training to provide a robust justification in ESA reports in the year 2010 - 2011. We will also explore the feasibility of providing a personalised summary as part of the ESA report before the end of 2011.

Evidence of application or success:

The year two Review said that a personalised summary statement for Atos assessors to complete was introduced nationally in June 2011, and that this has been used by Decision Makers.

Conclusion:

Implemented.

Recommendation 6

Harrington’s Recommendation:

The review recommends that every claimant is sent a copy of the Atos personalised summary and is able to discuss any inaccuracies with a Decision Maker.

Government’s Response:

Accept

It is essential that the basis of decisions is available and properly explained.

Evidence of application or success:

In the second year Review, it was clear that the Review had been in discussion with the DWP. The Review said that it had had “extensive discussions with senior DWP staff over this and understands the need to issue the statement to the right claimants, in the right context, at the right time.” The phrases “right claimants,” “right context” and “right time” suggest that the DWP and/or the Review was not intending at this stage to make the personalised summary available to all claimants.

It was suggested to the Review that it would be better “to issue the Decision Maker’s Justification instead if a claimant is disallowed,” on the basis of a trial carried out by the DWP over the summer. The Decision Maker’s justification would cover all of the evidence available, whereas the Atos assessor would use only the report they had written. A trial then began to issue the Decision Maker’s justification to claimants found fit for work, with the intention to implement this nationally – subject to the findings of the trial – to all claimants found fit for work from December 2011.

In Prof Harrington’s third review, he said that, “Decision Makers Reasoning is issued to claimants found fit for work with the aim of providing a clearer explanation of the decision and all the evidence considered by the Decision Maker.” The reasoning is “an extended piece of prose outlining the claimant’s case and the reasoning behind the DWP decision to allocate an individual to a particular Group.”

A survey conducted by Action for ME found that almost half of respondents did not see a copy of the report from their assessment. As this question does not refer to the Decision Maker’s justification (reasoning), it is unclear whether these claimants received the Decision Maker’s justification instead. However, it is clear that not all claimants see a copy of their WCA report, the Atos assessor’s personalised summary or the Decision Maker’s justification.

All three would be useful for all claimants. Claimants with long-term conditions may find it helpful to have all information from previous claims, particularly when contesting the ruling of the most recent decision. Claimants found Fit For Work or placed in the WRAG who wish to appeal are likely to find it helpful to have the WCA report *and* the personalised summary in order to discuss accuracy at a reconsideration or appeal.

Conclusion:

Partially implemented.

Claimants found fit for work only are sent a copy of the Decision Maker’s justification only. Other claimants do not receive this, and none routinely receive either the personalised summary or the WCA report.

Recommendation 7

Harrington’s Recommendation:

The review recommends that Atos provide mental, intellectual and cognitive champions in each medical assessment centre. These champions should ***spread best practice*** amongst Atos healthcare professionals in mental, intellectual and cognitive disabilities (emphasis added).

Government’s Response:

Accept.

DWP and Atos will establish healthcare professionals with enhanced skills as champions who will serve as a resource for all healthcare professionals.

Evidence of application or success:

The purpose of these champions, as stated by the Review in its first year report, was to “employ champions in mental, intellectual and cognitive disabilities. That is HCPs who have undergone further specific training in these conditions and are able to spread best practice and knowledge, help other HCPs with difficult assessment or take on some of the most difficult assessments involving mental, intellectual or cognitive disabilities.”

It was originally suggested that each assessment centre have a Mental Function Champion. This however was reported in the second year Review to be “logistically impossible,” so instead the DWP has put in place 60 MFCs on a regional basis. “The Review has been convinced that a regional approach is more efficient, conserving scarce resource and still delivering the desired result.”

Dr Gunnyeon reported that HCPs can always access Mental Function Champions: “There is always somebody available for healthcare professionals while they are doing an assessment, whether they want advice before they start an assessment, or to pause an assessment and go and seek advice, or to seek advice before they complete their assessment report.”¹⁷¹

From Atos’ perspective, Mental Function Champions are having a positive effect. According to the Review, Atos “said that their healthcare professionals found the Champions to be ‘a great resource’ and that they were of ‘great use to put any uncertainties into perspective.’” The Review further said that it had “met one of the Champions during its visit to an Atos Assessment Centre. He described being able to help healthcare professionals both locally and nationally. He had also built a series of contacts with Community Mental Health Trusts to ensure greater provision of further documentary evidence.”

The Review has further recommended that “the Department may wish to explore the outcomes of assessments undertaken by Mental Function Champions in their supportive ‘non-Champion’ role to see if there are significant differences from non-specialists undertaking mental function assessments.”

The survey carried out by the Disability Benefits Consortium in September 2012 revealed that over 70% of advisors were not aware of ATOS Mental Function Champions. Those that were aware believed that the Champions had little or no impact on the quality of assessments for people with mental health problems, learning disabilities and autistic spectrum disorders. This reflects anecdotal evidence from local organisations that it has been difficult to make contact with Mental Function Champions and, perhaps more importantly, that it has been far from obvious what role they are playing in improving the Work Capability Assessment.

Concerns about the poor quality of mental health assessments remain high and widespread amongst charities, advisers and claimants. According to the Papworth Trust, “3/4 of advisors

¹⁷¹ Work and Pensions Committee, 21st November 2012

say that people with mental health conditions were most likely to be incorrectly assessed. Advisors often reported feeling helpless when asked to support a client with severe MH needs who they know is unsuitable to work.”¹⁷²

A joint response from Centre for Mental Health, HAFAL, the Mental Health Foundation, Mind, Rethink Mental Illness, the Royal College of Psychiatrists and SAMH said that, “We believe that, without expertise in the causal conditions, healthcare professionals are not sufficiently equipped to understand why and how function may be impaired or to elicit the relevant information from an applicant who may have... difficulties in reporting their condition.” There is widespread feeling that MFCs should be health practitioners who had specialised in mental health *before* joining Atos as an assessor, not simply had extra training *after* joining Atos.

Conclusion:

Partial implementation with limited success.

Recommendation 8

Harrington’s Recommendation:

The review recommends that Atos pilot the audio recording of assessments to determine whether such an approach is helpful for claimants and improves the quality of assessments.

Government’s Response:

Accept.

Atos Healthcare has provision for the recording of medical assessments and we will shortly launch a pilot initiative to establish the feasibility and cost effectiveness of recording of all face-to-face assessments.

Evidence of application or success:

A pilot was carried out in Newcastle-Upon-Tyne Medical Assessment Centre in spring 2011. This trial offered audio recordings to 500 claimants, of whom 344 accepted and 230 recordings were made.¹⁷³

Prof Harrington reported that 70% of claimants in the trial thought that recording was a good idea, although this was split between those who agreed to a recording (85% considered it a good idea) and those who did not (36%). Only 47% thought they would find recording beneficial – it is difficult to interpret this in light of the previous statement.

The Atos assessors generally considered the recording as a positive procedure, and that it would support them if there were subsequent complaints. Most of the assessors “felt it would be appropriate for all HCPs to be required to undertake recordings if the recording were to be rolled out to all customers,” although there was recognition that some assessors may find this stressful.

The report suggested that audio recording did not improve the quality of the assessment. It did not consider the *accuracy* of the assessment in recording the claimant’s conditions and capabilities, a measure that might be considered more appropriate.

¹⁷² Papworth Trust, response to call for evidence for the third year Review

¹⁷³ 78 did not attend, 25 withdrew permission, and 11 were unable to have their assessment recorded

Prof Harrington concluded that, “The results of the pilot indicate that there are a significant proportion of clients who would welcome the opportunity to have their assessment recorded.” He also said that there is increasing demand for recordings, and that therefore “there is a need to make recordings more readily available on request.”

He recommends that “recording should be become routine as it is in a call centre or for example – NHS direct. There is therefore an urgent need to decide how the issue of recording of assessment is progressed and AH is keen to work closely with the Department to develop a measured and cost effective way of implementing this.”

The DWP have not done this. They have made audio recordings available on request – although claimants report that even after request a recording may not be made – but no information about this is available on either the relevant section of the DWP’s website or on the Atos website. Atos have only 5 recording machines,¹⁷⁴ to serve over 120 Medical Assessment Centres.¹⁷⁵ This is not close to Prof Harrington’s recommendation of universal recording, and cannot supply the number of claimants who, based on the evidence, would have a recording made if offered the opportunity.

The DWP’s reasoning is that, ““less than half of people wanted their sessions recorded and only a tiny number sought a copy of their recording.”¹⁷⁶ The Work and Pensions Committee challenged this, saying, “Asking for the transcript is not necessarily an indication of how useful it is, because the fact that it was recorded at all is the guarantee for the claimant that what they said is there and has been recorded. For instance, calls to the CSA1 are all taped, but very, very few people ask for the transcript. It is only when there is a problem that they ask for the transcript, but the knowledge that it is being taped means that they are probably less likely to ask for the transcript, because there is less likely to be a dispute. That is the point of the audio recording.”¹⁷⁷ Furthermore, the majority of claimants thought that a recording would be beneficial, as did the HCPs involved.

There does not appear to be good reason for the very poor provision of audio recording.

Conclusion:

Partial implementation with limited success.

Prof Harrington recommended universal recording. Instead, the government has provided only 5 machines available on request, but not guaranteed upon request, and no information is provided about this option on DWP, government or Atos websites.

Recommendation 9

¹⁷⁴ FoI request regarding the number and state of repair of Atos recording machines. Reply dated 12th August 2012 https://www.whatdotheyknow.com/request/state_of_repair_of_atos_medical

¹⁷⁵ 123 permanent centres plus some others. Evidence given to the Work and Pensions Committee by Mark Hoban, 2012

An FoI request regarding the accessibility as Medical Assessment Centres gave 139 centres. Reply dated 14th September 2011. https://www.whatdotheyknow.com/request/atos_assessment_centres_location

¹⁷⁶ Hansard, Mr Grayling, 22 Feb 2012 : Column 869W

<http://www.publications.parliament.uk/pa/cm201212/cmhansrd/cm120222/text/120222w0003.htm#12022278001695>

¹⁷⁷ Work and Pensions Committee, oral evidence on ESA and the WCA, 21st November 2012

Harrington's Recommendation:

The review recommends that Atos should develop and publish a clear charter of claimant rights and responsibilities, and should consider publishing the HCP guidance online for claimants and advisors.

Government's Response:

Accept

Evidence of application or success:

The Atos Customer Charter and WCA Handbook (HCP Guidance) are both available online.¹⁷⁸ The government has fully implemented this recommendation. It would be beneficial to see greater advertising of these resources, as 67.2% of the Disability Benefit Consortium respondents were unaware of the charter in 2011.

Despite the charter, claimants continued to have negative experiences with Atos. As reported in the third year Review, claimants with mobility problems continue to have difficulty with access, assessors attitudes remains poor, and "there appears to be an increase in individuals who, having submitted further documentary evidence from their GP or chosen healthcare adviser, feel this is ignored or overlooked at the face-to-face assessment."

Accuracy of reports continues to be an issue, with many claimants saying that the report "does not reflect their experience of the face-to-face assessment. Incorrect details are input or important points omitted, and assumptions are made about a claimant's condition." Those with complex health conditions continue to feel that their Atos assessor "does not have the necessary skills or training to complete the assessment."

Conclusion

Implemented with limited success

Recommendation 10**Harrington's Recommendation:**

The review recommends that Jobcentre Plus Decision Makers are put back at the heart of the system and empowered to make an independent and considered decision.

Government's Response:

Accept

Evidence of application or success:

The Review considers that the use of the 'Assurance Call' is "a good example of ensuring Decision Makers are driving the process." The success rates of calls is low with 1 in 3 calls getting through to claimants. According to the Review, much of the variation in success rate is "down to the attitude of local managers towards the increased workload on Decision Makers and the inevitable slowing in the number of claimants handled in a week."

Contact with Atos assessors remains variable, with many Decision Makers struggling to build relationships with assessors, and some assessors not engaging in reworking assessment

¹⁷⁸ <http://www.dwp.gov.uk/publications/specialist-guides/#other>
http://www.atoshealthcare.com/claimants/our_customer_charter

reports. The Review said that, “Communications between DWP Decision Makers and Atos healthcare professionals appear to remain variable. A common theme ... was an apparent difficulty in persuading Atos healthcare professionals to rework assessment reports. ... “Decision Makers appreciated the chance to discuss individual cases with Atos healthcare professionals when this facility was available, but building relationships through the phone advice-line was more difficult.”

Regarding decisions involving mental health conditions, the Review said that, “Decisions on mental function claims remain complex, with training and support seen as the key elements rather than the specific wording of the legislative descriptors.”

According to the third report of the Review, “Since the acceptance of the recommendations in the year one Review extensive training and development, and associated materials, have been developed for DWP Decision Makers. These have all been aimed at improving the skills and knowledge of Decision Makers to allow them to effectively sit at the heart of the WCA ... However, neither Review has been able to demonstrate satisfactorily the link between the training offered and the added value this offers to the individuals involved. Only then can the Review be assured that the WCA is being undertaken to a standard commensurate with the importance the benefit system demands.” (emphasis added)

The Review therefore recommended that, “In order to build on the progress already made DWP Operations need to find an appropriate balance between better quality decisions that are carefully considered and ‘right first time’ and the achievement of appropriate benchmarks at a local level, otherwise there is a real risk of derailing the positive progress made to date.”

It further commented that, “It was apparent that managers at different sites have a different approach to the implementation of the Review’s recommendations: some were still concerned about meeting the Department’s benchmarks whilst others have placed a stronger emphasis on the concept of ‘right first time’ decisions even if this takes more time.

It is important that claims are administered in a timely fashion, but the Review strongly supports the concept of ‘right first time’ decision making which takes into account all available information to support it.”

The Quality Assurance Framework shows that approximately 90% of decisions meet the current criteria. These are:¹⁷⁹

- The aim of the Decision Making QAF is to identify any fundamental errors, rather than minor mistakes that have no potential impact on the decision making process or the outcome.
- A fundamental error is where the outcome is wrong, the customer has not been treated fairly, or an important stage of the decision making process has been

¹⁷⁹ Data obtained by FoI request on the Quality Assurance Framework.

https://www.whatdotheyknow.com/request/quality_metrics_for_decisionmake#incoming-276968

handled incorrectly so that, even if the outcome was acceptable, there was potential for a wrong outcome.

- The standard set for Quality Checking requires that each of the following elements be met. A decision that fails on one or more of these points will not reach the required standard.
 - The crucial issues are correctly identified and the decision is focused on these;
 - The necessary evidence gathered has been used appropriately to establish the relevant facts, if any of these were missing, or to clarify any points of doubt;
 - The law, including the legislation, has been interpreted and applied correctly to the facts of the case;
 - The DM is neutral and the customer has been treated fairly;
 - The key conclusions and the reasons for them are recorded and the decision is soundly based in fact and law;
 - The outcome of the decision is one that is right in the circumstances.
 -

“In a very small sample of cases where the claimants were asked if they could recognise themselves in the Decision Maker Reasoning, 75 per cent stated they could. This is in marked contrast to claimants’ views from the call for evidence on the reports from the face-to-face assessment.”

Citizen’s Advice Scotland reported in their response to the second year Call for Evidence that, “Anecdotally, some advisers have reported an improvement in the role of DWP decision makers. One adviser explained how a decision maker took responsibility for helping a client get a reconsideration when the adviser showed that the initial assessment had been flawed. We hope that DWP decision makers continue to take an assertive role in the process.”

Conclusion:

Implemented.

Whilst this is a subjective recommendation, a number of things have been implemented to increase the role of the Decision Maker. There is some evidence that Decision makers are taking a more active role.

Recommendation 11

Harrington’s Recommendation:

The review recommends a better use of the reconsideration process.

Government’s Response:

Accept

An effective reconsideration stage is an important element of the decision making process. Considerable progress has been made in strengthening the process with the piloting of new measures at Wrexham and we will expand this experience nationwide.

Evidence of application or success:

In the first year, the Review found that the reconsideration process is “rarely used by Decision Makers” such that claimants are therefore reliant on “the more lengthy appeals process.” However, the DWP said in evidence to the Work and Pensions Committee that “If

a customer appeals this will also trigger the reconsideration process, as the Department aims to put decisions right at the earliest opportunity.”

Following a trial in Wrexham, where claimants were offered a reconsideration, “15% of claimants who had appealed either withdrew their appeal or had their initial decision revised.” The majority of these were revised. 254 claimants were involved in the trial. An FoI request elicited the following information:

- 1.2% of cases were withdrawn by the claimant;
- 13.8% of cases were revised; and
- 17.3% of cases were referred back to Atos.

The Review noted in its second year that, “Increased use of the reconsideration process is now a standard part of the later stages of the claimant journey. This is proving to be useful as additional medical information from the claimant often only comes to light at this stage. In an ideal world, the Decision Maker should have this evidence early in the process, but the fact that it is being considered routinely before an appeal needs to be invoked is an advance on previous practice.”

Claimants and welfare advisers say that they have seen an increase in the use of the reconsideration process – although CAB qualified this by saying that there has been “much less improvement in the original decision making.”¹⁸⁰ The Disability Benefits Consortium noted a similar response, with 35% saying they had seen an increase in the use of reconsideration, but only 11% “thought that a decision maker was more likely now to overrule the Atos recommendation in the original decision.”

Whilst evidence shows an increase in use of reconsideration, advisers are split about whether this is beneficial. Slightly more advisers considered that reconsideration had not “had a positive impact on claimants receiving a fair outcome” than considered there had been a positive impact (36% vs 32%).

Mandatory Reconsideration:

The government has now brought in a process whereby reconsideration before appeal is mandatory. The assessment rate of ESA is not paid during this time, as it is whilst waiting for an appeal to be heard. The government says that, “Although the claimant (or other person) could ask initially for the decision to be reconsidered with a view to revision [...] in practice many people do not do so and make an appeal from the outset.”¹⁸¹

Serious objections have been made to this. Sue Royston, Policy Officer for the Citizen’s Advice Bureau, said that, “At present, when somebody puts in an appeal, DWP has to reconsider that decision, so the reconsideration is there [...] what is being proposed is imposing two time limits on the client. The reconsideration would be done; the client would get the decision; and then they would have to put in an appeal again. They would have two

¹⁸⁰ CAB 2012

¹⁸¹ Work and Pensions Committee, 6th Report, Role of IB reassessment in helping claimants into employment. 2011

time limits to meet. That seems to me very wrong. It is putting the onus on clients to do the thing twice...

“We completely agree that an effective use of the reconsideration process is in everyone’s interest. We do not however, believe that DWP has given any convincing justification of why this measure is necessary in order to achieve this. We believe that nothing in this measure will strengthen the reconsideration process. At present, the DWP has to reconsider the decision when someone appeals. This step needs to be used much more effectively, especially in the case of ESA decisions.”

The Disability Benefits Consortium said that, “In our experience it is almost unknown for the DWP not to carry out a reconsideration when an appeal is received, even though there has been no legislative requirement to do so. In practice, virtually all decisions are reconsidered before the appeal proceeds and the consultation document notes that a significant proportion of appeals are currently lapsed at this stage. We cannot therefore view making reconsiderations mandatory having a significant impact on improving the system.”¹⁸²

The DWP themselves corroborated this in their evidence to the Work and Pensions Committee, saying twice that, “If a customer appeals this will also trigger the reconsideration process, as the Department aims to put decisions right at the earliest opportunity.” Sue Royston of CAB said that, “What we saw up until very recently is you would send an appeal in and, within the two days, you would get a decision back that it had been reconsidered. That reconsideration by DWP was basically a rubber-stamping of what had gone before. We saw very few properly reconsidered.”

In general, responses to this consultation suggested that:

- The original decision making needs to be improved;
- There is already a reconsideration process; making it ‘mandatory’ is unnecessary and will not add anything to the current process;
- Reconsideration needs to be properly used, not a rubber-stamp of the previous decision, but this will not happen as a result of adding extra bureaucracy on the claimant;
- Not paying ESA during this time is dangerous and discriminatory;
- Appeals can already take a year to be heard; this simply adds to the length of the process; and
- It adds extra bureaucracy and time limits that can be very difficult for ill, disabled and vulnerable people to meet.

Conclusion:

Implemented.

The government has gone beyond the Review’s recommendation to make reconsideration a mandatory part of the appeal process. There are multiple concerns with this as expressed by a number of charities. It is not the purpose of this report to go into these in detail, but it is noted that this is widely considered an unnecessary change and may cause harm to claimants.

¹⁸² <http://www.disabilityrightsuk.org/department-work-and-pensions-september-2012-mandatory-consideration-revision-appeal-our-response>

Recommendation 12

Harrington's Recommendation:

The review recommends Decision Makers are able to seek appropriate chosen healthcare professional advice to provide a view on the accuracy of the report.

This was clarified by the Review that 'chosen healthcare professional advice' means a healthcare professional chosen by the claimant; i.e. a report from the HCP named by the claimant as explained below (emphasis added).

"In summary, the Decision Maker has a pivotal role in evidence gathering. They should ask the claimant to name a chosen HCP and seek a report from them (for some claimants, the Decision Maker may have to undertake that task). When the Decision Maker has received the Atos report, including a personalised, free text summary (see Chapter 5), they will offer to send it to the claimant's chosen HCP. When a report has been received, the Decision Maker reviews all the evidence and commissioned reports, including the ESA50 questionnaire with free text paragraph (see Chapter 4). Following liaison with the claimant and, if necessary, Atos and the claimant's HCP advisor, the Decision Maker makes a decision."

Government's Response:

Accept

"Decision Makers should seek appropriate advice and/or additional evidence in coming to their determination if they require. Different approaches, e.g., with Atos healthcare professionals providing advice and support in interpreting evidence on site through case consultations or "surgeries" and or workshops/training events, are currently being trialled."

Evidence of application or success:

The DWP has put in place measures for Decision Makers to contact an Atos healthcare professional [recommendation 13, below], but has not arranged for Decision Makers to be able to contact the *claimant's* chosen Health Care Professional.

The government therefore has not carried out this recommendation.

The DBC survey confirmed that this does not appear to have occurred:

- Almost 75% disagreed that Decision Makers were "more likely to seek advice from the customer's chosen healthcare professional." Less than 8% agreed.

Conclusion:

Not implemented

Recommendation 13

Harrington's Recommendation:

The review recommends better communication between Decision Makers and Atos healthcare professionals to deal with borderline cases.

Government's Response:

Accept

Evidence of application or success:

In response to the first review, the DWP said, "To build on this progress [DMs telephoning claimants regarding their outcome], pilots are also underway to improve communication

between Decision Makers and Atos healthcare professionals.” They also indicated that Decision Makers already contact HCPs in some cases, and that this will be expanded.

As the Review recognised in its first year, pilots were already underway to improve communication between Decision Makers and Atos, having started in January 2010.

The Review said in its second year that, “Improving the communication between Atos HCPs and the Decision Makers has been trialled. The Review has seen at first hand that where this has been done it has been a valuable resource, particularly for Decision Makers who have had the opportunity to discuss difficult cases or complex medical evidence with Atos HCPs or to understand better the recommendations made by Atos following the face-to-face assessment. However, there has been no national roll-out of this, instead a telephone advice-line is being introduced.” This decision was made based on cost.

The Review commented in the third year report that, “Communications between DWP Decision Makers and Atos healthcare professionals appear to remain variable. A common theme ... was an apparent difficulty in persuading Atos healthcare professionals to rework assessment reports. ...

“Decision Makers appreciated the chance to discuss individual cases with Atos healthcare professionals when this facility was available, but building relationships through the phone advice-line was more difficult.”

Decision Makers may contact the Atos HCP who carried out the assessment, or contact a separate HCP for general advice.

Conclusion:

Implemented with limited success.

For cost reasons, a telephone line has been introduced rather than have Atos HCPs at all decision maker centres.

Recommendation 14

Harrington’s Recommendation:

The review recommends Decision Makers receive training so that they can give appropriate weight to additional evidence.

Government’s Response:

Accept

Evidence of application or success:

The DWP has launched a forum for Decision Makers, “to spread best practice and empower Decision Makers.” Additional support tools include a “Quality Assessment Framework to improve the consistency of decisions,” and the government has also reviewed its Learning and Development. The Review commented in its third year that, “extensive training and development, and associated materials, have been developed for DWP Decision Makers. These have all been aimed at improving the skills and knowledge of Decision Makers to allow them to effectively sit at the heart of the WCA.”

It is not possible to comment on the efficacy of this training without further data on the quality, consistency and accuracy of Decision Maker's decisions.

The government mentions training generally, not specifically so that Decision Makers "can give appropriate weight to additional evidence." The responses to the DBC's most recent survey suggest that any training is not having noticeable effect:

- Almost 75% disagreed that they had "been more likely to seek advice from the customer's chosen healthcare professional."
- Over 65% disagreed that they had "given greater weighting to additional medical evidence."

Conclusion:

Implemented with limited success.

The DBC reports that Decision Makers are not thought to be using medical evidence appropriately.

The third Review has resulted in the recommendation that, "Decision Makers should actively consider the need to seek further documentary evidence in every claimant's case. The final decision must be justified where this is not sought."

Recommendation 15

Harrington's Recommendation:

The review recommends that feedback from the First-tier Tribunal should be routinely shared with Jobcentre Plus staff and Atos healthcare professionals. As part of their professional development, Jobcentre Plus Decision Makers should be encouraged to regularly attend Tribunals.

Government's Response:

Will consider this recommendation, which is largely the remit of the First-tier Tribunal

Evidence of application or success:

The First-tier Tribunal indicated to the Review and the DWP that the actions of the tribunal are beyond the Review's remit.

A summary feedback form has been developed for tribunals to send to the Decision Maker. Results of this have already been released, showing that new oral evidence is the main reason for appeals to be over-turned, followed by the tribunal reaching a different conclusion on the same evidence.

It does not appear to be the case that Tribunal decisions are sent to Atos healthcare professionals.

Conclusion:

Partially implemented.

Whilst feedback is sent to Decision Makers, it does not appear to be sent to Atos assessors. Nor does it seem to be the case that Decision Makers regularly attend Tribunals.

Recommendation 16

Harrington's Recommendation:

The review recommends that Tribunal decisions are better monitored, including monitoring of the relative or comparative performance of Tribunals.

Government's Response:

Will consider this recommendation

Evidence of application or success:

This has not been carried out. In its second year, the Review said, "No progress has yet been made with the recommendation concerning the monitoring of appeal outcomes within and between Tribunals."

This is particularly concerning given that the Review went on to say that anecdotal evidence suggests there is wide variation in appeal outcomes between Tribunals and between individual judges.

Conclusion:

Beyond remit

Recommendation 17

Harrington's Recommendation:

The review recommends that training offered by the Chamber President to Tribunal Judges and medical Members should include modules on the evidence of the beneficial effects of work to an individual's well-being.

Government's Response:

Will consider this recommendation

Evidence of application or success:

In the second year Review, the Review explained that it is not the responsibility of First-Tier Tribunal Judges to consider socio-medical issues. This recommendation was therefore not pursued.

Conclusion:

Beyond remit

Recommendation 18

Harrington's Recommendation:

The review has asked Mind, Mencap and the National Autistic Society to provide recommendations on refining the mental, intellectual and cognitive descriptors. The review looks forward to receiving these recommendations in late November and will make any recommendations it sees fit to Ministers.

Government's Response:

Accept

Evidence of application or success:

Mind, Mencap and the National Autistic Society submitted reports on ESA descriptors to a Scrutiny Group in December 2010. The Scrutiny Group 'broadly agreed' with the proposals, and the Review endorsed them and submitted them to the DWP in April 2011. The DWP considered that the proposed new descriptors were not sufficiently evidence based, and therefore the DWP would not incorporate them into ESA.

The DWP agreed to build an evidence base, known as the ‘Evidence Based Review’ or ‘Gold Standard Review.’ It was hoped that the results would be released in early 2013, but this has not happened.¹⁸³ Instead, it was suggested during a debate in November 2012 that some results may be made available in the spring of 2013, with a full report in the summer.¹⁸⁴ By April 2013, this had moved to the study occurring some time between April and July. The government has accepted the recommendation, but understandably it is taking time to implement.

Dr Gunnyeon reported on the progress of the review to the Work and Pensions Committee. He said that, “There are a number of components to the work we have been doing; the first one was to take the descriptors that were in a very general form, which the charities recommended, and to work with them to try to develop those into a format that would be testable, because clearly that is the first stage. That has been quite time-consuming. We have had something of the order of 25 to 30 meetings with the charities as we have developed the descriptors, but it has been incredibly helpful. We then have to put a process in place to test our current descriptors against those new descriptors, and that means that we have to train the healthcare professionals who are going to do the testing, so there is obviously quite a bit of work there. Having done the assessing of a not insignificant number of cases, and we are looking at doing 1,000 cases, there is then a need to put in place the expert panels that will look at the outcome of the existing descriptors, the outcome of the new descriptors and determine how they think that relates to their assessment, given the information about that individual case—whether or not they think it would have been reasonable to expect them to work. On top of all of that, we have to have an evaluation strategy, because clearly the most important aspect of this is to be able to determine, at the end of the day, whether the new descriptors work and whether they work better than the existing descriptors.”¹⁸⁵

Conclusion

Implemented and still in progress

Recommendation 19

Harrington’s Recommendation:

In year two the review should examine the descriptors, in particular how they account for other fluctuating conditions and, possibly, generalised pain and provide any recommendations necessary.

Government’s Response:

Accept

Evidence of application or success:

¹⁸³ Chris Grayling, Hansard, 25 Jun 2012 : Column 53W, “We hope to publish a report of the evidence-based review in the spring of 2013.”

<http://www.publications.parliament.uk/pa/cm201213/cmhansrd/cm120625/text/120625w0002.htm#12062541000635>

¹⁸⁴ Dr Gunnyeon, Hansard, 28th November 2012 “The full report, because of some of the detailed evaluation, may be in the summer, but we still expect to have some results during the spring.”

<http://www.publications.parliament.uk/pa/cm201213/cmselect/cmworpen/uc769/uc76901.htm> N.B. neither witnesses nor Members have had the opportunity to correct the record. The transcript is not yet an approved formal record of these proceedings.

¹⁸⁵ WPC, 21st November 2012

“In January 2011 a group led by the MS Society and also containing Arthritis Care, Crohn’s and Colitis UK, Forward ME, the National AIDS Trust and Parkinson’s UK were asked to provide recommendations on refining the approach used to assess fluctuating conditions in the WCA.” As with the above group, the recommendations were submitted to an independent Scrutiny Group, in April 2011. Together they presented recommendations to the Review in November 2011. The Review endorsed these recommendations and submitted them to the DWP.

The DWP had the same reservations as for the submission on mental, intellectual and cognitive descriptors: that there was no evidence base. These descriptors have therefore been incorporated into the Evidence Based Review, with results to be released some time in 2013.

Conclusion:

Implemented and still in progress

Recommendation 20

Harrington’s Recommendation:

In year two the review should examine what happens to people who are found Fit for Work, people who are placed in the Work-Related Activity Group, in the Support Group and people who do not complete their WCA.

Government’s Response:

Accept

Evidence of application or success:

A qualitative published in 2012 considered those had been found Fit For Work.¹⁸⁶ This excluded those who had closed their claim, and those who had appealed but not yet had an outcome.

Most of those whose claim had been closed or withdrawn said this was because their health had improved, and so they closed their claim. A small number had their claim closed because they had not carried on the process, in some cases because life events or the claimant’s condition made it too difficult.

Of those found fit for work, “the view that it was ‘pointless’ to appeal was widespread.” Some agreed to some extent, but others disagreed strongly, with their claim outcome. Some felt unable to claim JSA, because their health meant they could not comply with the work search and availability requirements. Most of those who had moved on to JSA “reported that they had received little individualised support that took into account their health problems.”

Lack of money resulted in people “borrowing, spending savings, going without prescriptions and changing to interest-only mortgages.”

A more detailed quantitative study found the following:

¹⁸⁶ Barnes, Oakley, Stevens and Sissons 2011 Unsuccessful ESA claims – qualitative research. DWP

ESA outcome category	Percentage in work 12–18 months after claim
-----------------------------	--

All ESA claims	25%
Fit for Work	25%
Work Related Activity Group	9%
Support Group	10%
Claim closed or withdrawn	39%
Claim in progress	22%

Of note are:

- People in the WRAG – who ostensibly are in better health and who receive work-related support - are no more likely to be in employment than those who are placed in the Support Group.
- Despite most of those who closed their claim doing so because their health improved, the majority are still not in work after 12-18 months
- Only 25% of those who are found fit for work are in employment 12-18 months later.
 - This group in theory should not face significantly greater health barriers to employment than do people on Jobseeker's Allowance, yet
 - 80% of people on Jobseeker's Allowance leave within 6 months, with most of these returning to work¹⁸⁷

The Review also found that *for claimants awarded ESA* those who had had a job prior to claiming were more likely to be in a job 12-18 months later, at 26 vs 9% of people. Of those *either* found Fit For Work *or* who closed their claim, the difference was 48% compared to 21%.

These figures, combined with the overall figures, suggest two things:

- Most ESA claimants were *not* in work prior to their claim;
- Being in work prior to the claim has a substantial effect on the likelihood of being in work 12-18 months later. This may be because:
 - People with worse conditions are less likely to have been in work prior to their claim *and* less likely to be in work 12-18 months after the claim
 - Employer's attitudes and willingness to accommodate has a substantial effect on the ability of those with chronic health conditions to find a suitable job, as it may be easier to return to a previous employer than to be taken on by a new employer

Conclusion:

Implemented

Recommendation 21

Harrington's Recommendation:

In year two the review should examine what happens to people who are found Fit for Work but are unable to claim Jobseekers Allowance.

Government's Response:

Accept

Evidence of application or success:

¹⁸⁷ Data available from www.nomisweb.co.uk

In the second year, the Review examined what happened to people who were found Fit For Work but considered themselves too ill to work, or who are still in employment and would have to leave that employment to qualify for Jobseeker's Allowance.

The Review suggested – based on anecdotal evidence - that some of those found Fit For Work may be unhappy with that decision because they had not had “a proper explanation of the decision ... or the subsequent help and support available to them.” He considered that this “lack of clarity” could lead to appealing or making a new claim. Also implicated by the Review were “Personal Advisers in DWP Operations who tell claimants they cannot understand how the Fit for Work decision was reached.” He felt that this inconsistency within the DWP may further contribute to the appeal/new claim cycle.

For those still employed, the Review recommended that the employer should consider reasonable adjustments; changing JSA legislation would be beyond the remit of the Review. He thought that Universal Credit may provide solutions to this problem.

Lack of money resulted in people “borrowing, spending savings, going without prescriptions and changing to interest-only mortgages.”

“Some customers described moving between JSA and ESA relatively frequently, over both the shorter and longer-term. This meant the back-to-work support they were receiving was fragmented and rather inconsistent.”¹⁸⁸

Conclusion:

Partially implemented.

A qualitative study has been carried out to find out what happens to this group of people, but no detailed or quantitative study.

Recommendation 22

Harrington's Recommendation:

In year two the review recommends that research is undertaken to understand whether the assessment could and should incorporate more “real world” or work-focused elements.

Government's Response:

Accept

Evidence of application or success:

The Citizen's Advice Bureau was invited to present recommendations on this subject to the Review in July 2011. It was intended that a seminar be held in the autumn with the TUC, CBI, Work Programme Providers, Departmental Officials and representative groups.

It was considered that the report did not offer clear or evidence based advice, and “lacked any information on what objective, measurable and fair criteria could be used to assess ‘employability,’” The above mentioned seminar was therefore not held, and the Review was unable to commend the report to the DWP.

¹⁸⁸ Barnes, Oakley, Stevens & Sissons, 2012, Unsuccessful Employment and Support Allowance claims – qualitative research <http://research.dwp.gov.uk/asd/asd5/rrs-index.asp>

It was felt that a real-world test would take too long to be incorporated in the WCA, and “poses many challenges” with “a number of practical considerations.”¹⁸⁹ Instead it may be better to improve communications with the Work Programme providers.

The Review said that it, “welcomes the on-going and constructive dialogue with Citizens Advice Bureau and will continue to work with them to explore some of their recommendations in more detail.”

There appears to be some conflict of opinion over the definition of ‘real-world test.’ Dame Anne Begg, the chair of the Work and Pensions Committee, put to Chris Grayling that,

“the WCA does not ask the questions about real life chances of that individual getting a job. It does not take into account labour market conditions in the area, educational ability or ability to retrain or any of that. Now, we have been told that it takes the contractors’ personal advisers about 15 minutes to decide if somebody is work ready or not. They are obviously using different criteria and a different assessment from the WCA. Is there any way that the WCA can start to take into account that kind of real life experience to make a more sensitive judgment as to just how work ready someone is? So it is not just a, “Yes, that person can work,” but also there is a second part to their assessment, which is, “Yes, they can work, but they will need this particular type of help and it is probably in these areas that they are going to be able to work.” Now, I understand that Professor Harrington is suggesting that that should be part and parcel of the process of the assessment as well.”

Chris Grayling’s response was that,

“The one thing I am absolutely unreservedly and implacably opposed to in all of this is a real world test. Either somebody is fit for work or they are not, and what I am not prepared to do is to countenance a situation where we are saying: “You are fit for work, but you should not be on JSA because there is high unemployment in your area.” ... But what I do not think we could possibly countenance is the situation where we are saying, “Because of circumstances in the labour market in your area, we will treat you differently.” I think that would be a huge mistake.”

Mr Grayling’s response suggests that he thinks of a ‘real world test’ as referring to the local job-market conditions. However, disabled people and organisations may think of a ‘real world test’ as meaning that there is explicit consideration of exactly what work the claimant is expected to be capable of. That is, there is a link to real work, not theoretical work that may not exist anywhere in the country.

This was considered in the Work Focused Health-Related Assessment that occurred after the WCA assessment for claimants placed in the Work Related Activity Group. “The WFHRA – which, initially at least, took place on the same day as the medical assessment and usually involved the same Atos healthcare professional – focused on what the claimant was capable of doing and how their condition might be managed to help them obtain or stay in work.

¹⁸⁹ Employment Related Services Association (ERSA), response to second call for evidence.

The purpose was to explore the claimant's views about returning to work, what difficulties they faced in doing this, what they thought they could do to move back into work, and to identify health-related or workplace interventions which could support a move back to work. Following the assessment, the healthcare professional compiled a report for the claimant's Jobcentre Plus Personal Adviser, to facilitate discussion of appropriate goals in subsequent Work-Focused Interviews (WFIs)."¹⁹⁰

The WFHRA was suspended for two years from 19th July 2010 to allow the DWP to re-evaluate its resources given the introduction of the Work Programme. It is unclear why the WFHRA has not been re-introduced in the past year.

Conclusion:

Partially implemented without success

Recommendation 23

Harrington's Recommendation:

In year two the review should examine the Atos computer system (LiMA) and how it can drive the right behaviours.

Government's Response:

Accept

Evidence of application or success:

The first review received comments that the computer system, Logical Integrated Medical Assessment (LiMA), can drive Atos assessors' behaviour and decisions, and lead to an impersonal and mechanistic assessment.

The Review observed the use of LiMA in several environments. It noted that "considerable changes have been made to the system in the last year." The logic of the system was sound, acting constructively to point Atos assessors to linked elements and providing guidance and structure. Atos assessors "remain in control."

Atos assessors are being increasingly encouraged to use the free text boxes, including the new personalised summary statement, as this allows for more individualised reports. They are also encouraged to have 'soft skills,' and the Review has noted that adequate IT skills are an important part of being able to maintain personal approach. IT training is available as an e-learning tool for Atos assessors to "complete as they see appropriate." The Review "hopes" that this is monitored, "both to track demand and identify any changes in amounts of free text used in reports," but appears not to know if this is the case.

The DBC survey shows that the behaviour of Atos assessors continues to be concerning to clients. Whilst Atos assessors are encouraged to develop 'soft skills' and to use the free text box, this does not appear to have improved the experience for claimants.

- "Almost 80% disagreed that assessors had "given more weight to the free text box on the ESA50 where applicants can describe how their disability affects them.""

¹⁹⁰ The Work Capability Assessment for Employment and Support Allowance, SN/SP/5850, House of Commons Library, February 2011, para 2.4

- “Over 80% disagreed that assessors had “acted more sensitively towards applicants during assessments.””

The use of free text boxes by Atos assessors is now encouraged. This is monitored, with assessors in the highest and lowest deciles each month being identified. According to the Review, “there are considerable differences between the lowest and highest deciles.” Without further information the importance of this cannot be estimated. It is concerning that some assessors use substantially less free text, and it would be very useful to compare this to accuracy of reports.

Conclusion:

Implemented with partial success.

Recommendation 24

Harrington’s Recommendation:

In year two, the review should explore the use of other healthcare professionals in the Atos assessments and to check consistency of assessments by different professions.

Government’s Response:

Accept

Evidence of application or success:

The Review considered 34 000 cases to assess the consistency of Atos assessors, particularly any differences between different professions (doctor, nurse or physiotherapist). This showed that “nurses are slightly less likely [than expected] to recommend points against physical health descriptors and physiotherapists are slightly less likely [than expected] to recommend points against mental function descriptors.” Doctors overall recommend more points, but they also see the more complex cases, so to some extent this is to be expected.

		Doctor	Nurse	Physiotherapist	Total
	All cases	11670	20720	1420	33810
physical %	6 points	8	6	10	7
	9 points	3	2	2	2
	15 or more	9	7	8	8
	Any points	20	16	20	17
mental %	6 points	5	5	4	5
	9 points	2	2	1	2
	15 or more	11	10	9	10
	Any points	17	17	15	17
	Total any points	37	32	35	34

The Review concludes that, “The results show broadly consistent findings between HCP groups,” and that “The consistency of these findings would suggest that Atos’s training and audit of HCPs is having the desired outcome and that, regardless of profession, face-to-face assessments are being undertaken in a reliable manner.”

However, the differences between professions are highly significant. Whilst it is not possible to determine whether the higher level of physical points awarded by doctors is due only to them seeing more point-worthy cases – and not due to their greater medical expertise – it is concerning that nurses and physiotherapists vary in the points they award. The fact that physiotherapists under-award for mental illnesses whilst nurses under-award for physical illnesses may indicate a medical-knowledge issue here.

It may be the case that nurse’s lack of knowledge of physical conditions means they do not recognise the full extent of people’s physical disability here; vice versa, physiotherapists may be underestimating the extent to which mental conditions limit work capability. Equally it may be the case that doctors’ greater medical knowledge gives them a better appreciation of the effect of people’s conditions on their ability to work.

The Disability Benefits Consortium asked respondents how well they thought their assessor understood their conditions. The answers were divided into those whose assessment was before 2011, and those after. The results below are for those assessed in 2011 or later, indicating that this concern continues.

- 66% of respondents considered that the assessor did not understand their impairment or health condition.
- 68% “stated that the assessor did not take into account how their symptoms/aspects of their impairment or health condition change/fluctuate.”

Claimants clearly feel that assessors are inadequately qualified. The majority - 65% - of assessments are carried out by nurses or physiotherapists, who do not award as many points as doctors do, and who also show under-awarding of points for physical and mental conditions respectively. It is concerning for the claimants that the qualification of their assessor can have an effect on the outcome of their claim.

Conclusion:

Implemented.

It is concerning that the qualification of an assessor can have an effect on the outcome of a claim.

Recommendation 25

Harrington’s Recommendation:

In year two the review should also monitor the implementation of those recommendations in the year one report which have been adopted by Ministers.

Government’s Response:

Accept

Evidence of application or success:

The Review stated in its second year that, “The Government immediately accepted all of the recommendations.” A further recommendation was added in January 2011, asking Macmillan Cancer Support to review the provisions for claimants receiving treatment for cancer.

The Review said that, “Whilst there is firm evidence of change for the better in the way DWP has enthusiastically accepted the challenge presented by the Review’s

recommendations, less concrete evidence exists to show that Atos have done all they could to play their part in improving their section of the WCA.”

“Implementation of the recommendations around the face-to-face assessment appears, from anecdotal evidence, to be patchy. The variability in the quality of Atos performance was a frequent complaint received from Decision Makers during the Review’s unannounced visits.”

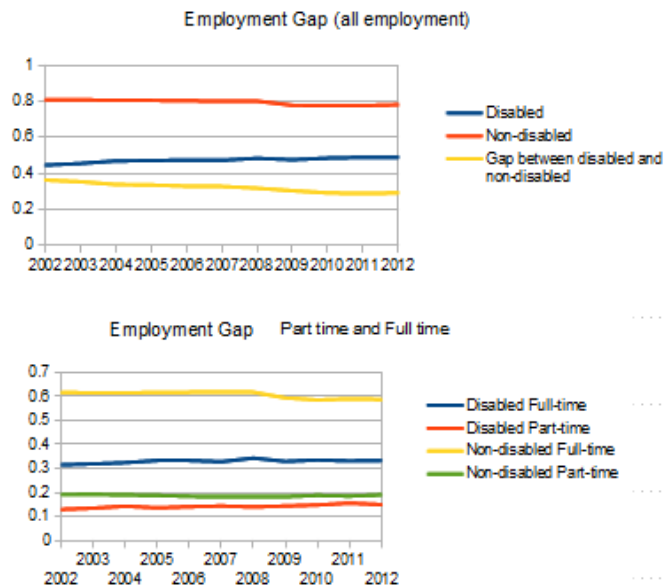
Whilst this report cannot agree that the government has fully or successfully implemented all the recommendations, it can confirm that the Review has monitored the implementation of these recommendations.

Appendix D: The Employment Gap

Figure 4.1

Myth : “The Employment Gap can be reduced if disabled people wanted to work”

Historic employment gap has decreased, even during the recent recession.



<http://odi.dwp.gov.uk/disability-statistics-and-research/disability-equality-indicators.php#b1>

Figure 4.2

Myth :The Employment Gap is too large, and too many people are economically inactive and on benefits.

- The Employment gap is less than 30 (percentage points)
- The Economic Inactivity gap is 31 (percentage points)
- However of the inactive disabled group 29% WOULD like a job, as opposed to only 22% of non-disabled inactive people
- If all these unemployed people and inactive people who wished to work from either group were helped into work, then the Employment gap would be less than 20 percentage points.

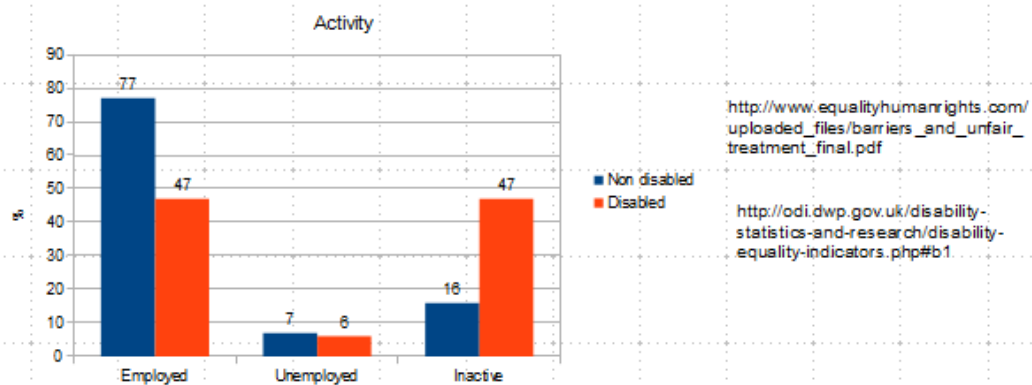


Figure 4.3

Main reason for inactivity among people aged 16 to 64 in Great Britain, by disability, July to September 2012

	Non-disabled%	Disabled%	All economically inactive%
Looking after family or home	35	14**	27
Student	32	4**	22
Sick, injured or disabled	2	63**	25
Other reason	30	19**	26
Unweighted bases (N)	8,245	5,290	13,535

Source: Labour Force Survey Q3 2012.

Notes: Reference groups are shown in bold. Significance testing which compares each group with the related reference group is indicated as follows: * significant difference at 95% level; ** significant difference at 99% level.

Remember, 29% of inactive disabled people want to work.

Only 22% of non-disabled people want to work.

Both groups face barriers to work that are the same.

However disabled people face numerous additional barriers to work and participation.

39 per cent of all unemployed adults seeking work were limited in the type or amount of paid work they could do.

58 per cent of adults with impairment who were unemployed and seeking work were limited in this way compared with 31 per cent of adults without impairment who were unemployed and seeking work – a percentage gap of 27.

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/180891/lfs_wave_one_200911.pdf

Figure 4.4

There are different approaches to measuring the number of disabled people in the United Kingdom, hence statistical analysis can vary.

Long-standing illness (GLS 2010) 30%

Covered by Equality Act (FRS 2010/11) - 19%

In receipt of disability related benefits (ESA/IB, DLA, AA) - 10%

(this figure can include some double counting, and can also include people not of working age.)

The DDA/EA2010

The Employment Gap caused due to barriers to work will always be difficult to gauge. Since 2010 the DDA and Equality Act mean that many people who would not be classed as sick or disabled under the benefit system are classed as disabled under the DDA/EA2010.

Whilst in work, many would not self-identify as disabled, as their disability is minimal and does not affect their ability to work.

When unemployed they may feel that a minor disability is giving them a disadvantage in the employment market, and so more readily define themselves as disabled with respect to the DDA/EA2010.

An additional problem is that available data becomes distorted by the influence of the DDA/EA2010, so comparative data sets are not available.

Hence the figures for employed disabled people could be estimated too low, as they don't self identify.

Similarly those unemployed may feel that they are now disabled, as they are covered by the DDA/EA2010, and may feel (rightly or wrongly) that they are at a disadvantage.

Figure 4.5

Who are most inactive by condition/impairment or other variable?

The following two slides indicate those who are inactive by age and condition. They can be summarised as follows;

Most inactive by age; - 16 – 24
- 55 - 64

The employment gap for 16-24 group is 36% less than the other age groups, and closer to the levels for their age group.

The 55-64 group has the highest level of economic inactivity but the lowest level of unemployment, suggesting that retirement and other income streams are used.

Most inactive by condition - Depression, bad nerves
- Epilepsy
- Learning Difficulties
- Mental illness, phobia and panics

The high levels of inactivity and low levels of employment for those with mental illness, phobias and panics indicates how far this group are away from participation

Conditions such as learning difficulties and progressive illness show relatively high levels of inactivity. Whilst it is entirely acceptable that those with progressive conditions refrain from work, or may be restricted by health to participate, which may not be beneficial for them, the same cannot be said for all of those with learning difficulties. This suggests that barriers to participation may not be being identified or addressed successfully for this group.

Figure 4.6

Who are inactive by age?

Table 2.8: Economic status of disabled people aged 16 to 64 in Great Britain by age, July to September 2012

Age	Employed%	Unemployed%	Economically inactive%	Employment gap (percentage points)	Unweighted bases
16-24	35	16	48	-19	754
25-34	50**	10**	40**	-32	1,187
35-44	54**	7**	38**	-33	2,002
45-54	55**	5**	40**	-34	3,078
55-64	38	3**	59**	-31	4,171
All	47	6	47	-30	11,190

Source: Labour Force Survey Q3 2012.

Notes: Reference groups are shown in bold. Significance testing which compares each group with the related reference group is indicated as follows: * significant difference at 95% level; ** significant difference at 99% level. Significance testing is not included for the employment gap.

Figure 4.7

Economic status of people aged 16 to 64 in Great Britain by main health problem or disability, July to September 2012

	Employed %	Unemployed %	Economically inactive %	unweighted bases
Arms or hands	59	5	36	1117
Legs or feet	59	6	35	2,279
Back or neck	62	5	33	2640
Difficulty in seeing	59	6	35	314
Difficulty in hearing	64	11**	25**	398
Speech impediment	-	-	-	[13]
Skin conditions, allergies	71**	8*	21**	546
Chest, breathing problems	69**	7*	24**	2678
Heart, blood pressure, circulation	69**	5	26**	2985
Stomach, liver, kidney, digestion	69**	6	25**	1375
Diabetes	70**	5	25**	1298
Depression, bad nerves	42**	12**	45**	1297
Epilepsy	52*	8	40	284
Learning difficulties	35**	13**	52**	418
Mental illness, phobia, panics	21**	9**	70**	686
Progressive illness	45**	3*	52**	815
Other	65**	6	28**	2461
All	61	7	32	21604

Source: Labour Force Survey Q3 2012.