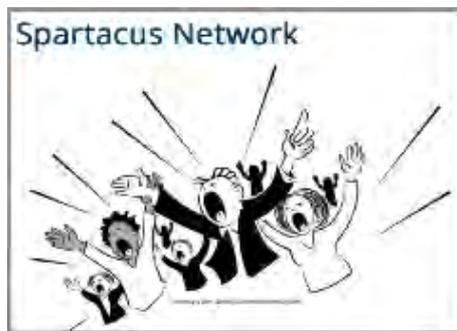


# Beyond the Barriers

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



**About us:** The [Spartacus Network](#) is a group of sick and disabled people, collaborating online and analysing government policy on welfare reform, ESA, WCA, the Work Programme and more. It began in 2012 with the report *Responsible Reform* on DLA. (Spartacus reports are also available via the Centre for Welfare Reform [here](#) and Spartacus material can be found on Ekklesia [here](#))

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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 impairments.
2. The report draws on a wide range of international data, UK evidence and case studies as the basis for any conclusions, giving weight to both 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, 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 were the worst aspects of ESA and work capability assessments (WCAs). The responses indicated that:**
  - 50% considered one of the worst parts 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 among the worst parts;
  - 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.

**6. The report considers a wide range of international data** from Australia, The Netherlands, Germany, 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, holistic assistance should start once Statutory Sick Pay is claimed, 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 physical or mental impairment and, by reason of such disease or impairment, 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 holistic, 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 physical, attitudinal and policy 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.
- That the assessor have experience in the relevant impairment or health condition.
- Once the process of assessment is complete, evidence should still be submitted to an independent Decision Maker.
- 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 where appropriate.
- Including the claimant's workplace in interventions where possible/applicable.
- Disability specific support and evidence-based practice.

**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.
- All WCAs to be recorded.
- Detailed consideration of the consequences of having a relevant specialist carry out the assessment and decision making (in particular for mental health and fluctuating conditions), in light of the findings from the Evidence Based Review.
- 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 5% achieved a Job Outcome, while for those transferring from the previous Incapacity Benefit the figure is just 1.8%.** 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 recommend 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.

- Making it easier to move between benefits and work fluidly
- Improved information on and access to further education and training.
- More employer engagement and more done to encourage, 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.
- Introduce a Volunteer's Credit and a Carer's Credit to the National Insurance system to recognise the contributions made by these groups.

**11.** We provide more in-depth analysis in the Appendices, which cover the policy assumptions underpinning ESA, an analysis of how successfully the recommendations made in the first year Review of the WCA have been implemented, and a critique of the concept of the 'employment gap' in UK policymaking.

**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 provision.

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 where appropriate and we recommend ways to overcome some of the greatest barriers to work faced by people living with long term or degenerative illnesses, mental health conditions 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 is not 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;
- Omissions from Atos reports;
- Variability in Atos assessments;
- Inaccuracy of guidelines for assessors;
- Variability in decision making;
- 43% success rate at appeal;
- A majority of overturned appeals overturned on new oral evidence;
- Low employment rate of claimants 12-18 months after starting a claim; and
- Exclusion of wider context in decision making.

ESA is flawed in principle, with an inappropriate medical-model basis and use of simplistic descriptors and points.

### 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.<sup>1</sup> Meanwhile, a study on the use of reconsideration by Decision Makers found that 17.3% of cases were referred back to Atos.<sup>2</sup>

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. Omissions.**

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."*<sup>3</sup>

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<sup>1</sup> CAB, Right First Time, 2012.

<sup>2</sup> CAB, Right First Time, *ibid*.

<sup>3</sup> National AIDS Trust response to Work and Pensions Committee:

<http://www.publications.parliament.uk/pa/cm201012/cmselect/cmworpen/writev/1015/esa15.htm>

The Muscular Dystrophy Campaign said,

*“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.”<sup>4</sup>*

## **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. 43% success rate at appeal.**

The latest data shows that for the past three quarters, 43% 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;<sup>5</sup>
- 94% at Oxford Welfare Rights;<sup>6</sup> and
- 100% at a London HIV organisation.<sup>7</sup>

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.<sup>8</sup>

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

<sup>5</sup> Dryburgh, 2010

<sup>6</sup> Oxford Welfare Rights written evidence submitted to Work and Pensions Committee

<sup>7</sup> National AIDS Trust response to Work and Pensions Committee, op cit.

<sup>8</sup> See Appendix 1 for quotes.

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.

## **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.<sup>9</sup>

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 the same evidence but a 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.”<sup>10</sup>*

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 starting a claim.**

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 as, or at a comparable rate to, people claiming Jobseeker’s Allowance (JSA).

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

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

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.<sup>11</sup>

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 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.

## **9. Exclusion of wider context in decision making.**

The activities used in ESA are medically based, referring not to skills or qualifications but to functional ability. The wider context is deliberately excluded. GPs however have previously suggested that social factors should be considered when assessing capacity for work.<sup>12</sup> In a recent survey conducted by Spartacus, 94% of respondents said that wider factors should be taken in account. International evidence also shows that valid assessments of capacity for work must include factors beyond medical function.<sup>13</sup> None of the factors suggested in our survey received less than 60% support.<sup>14</sup> That ESA does not consider these is a major flaw. However Mr Grayling, whilst in the role of minister for work and pensions, made it very clear that he would not accept a real world test.<sup>15</sup>

Because ESA deliberately does not consider what work might be possible, it also ignores what support would be needed and whether that support exists (ESA was originally supposed to consider these issues but this part was dropped following difficulties surrounding the timing of its implementation).<sup>16</sup> Consequently people can be found fit for work yet still be unable to carry out work.

ESA is unable to adequately assess people with mental health conditions<sup>17</sup> or with fluctuating or variable conditions.<sup>18</sup> The points-based system is particularly unsuited to

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<sup>11</sup> Data available from [www.nomisweb.co.uk](http://www.nomisweb.co.uk)

<sup>12</sup> Tellnes et al., 1990

<sup>13</sup> Dekkers-Sanchez et al., 2013.

<sup>14</sup> Spartacus. Appendix - table of wider factors and percentage who agree with including that factor in assessment.

<sup>15</sup> DWP, 2011

<sup>16</sup> Barnes et al., 2010.

<sup>17</sup> MHRN, 2013

<sup>18</sup> Harrington, 2010

chronic illness as it assumes problems are additive; e.g. that being unable to perform two three-point activities is equal to being unable to perform a six-point activity. Spartacus has seen no evidence that this is the case and the experience of disabled people may indicate a greater-than-additive interaction (e.g. two three-point activities might equal one nine-point activity). A more suitable approach may be that used with DLA where general statements that can be fulfilled in a number of ways are used; an example might be 'unable to work X hours a week' which, if set at an appropriate level, could be used as a qualifying criterion for ESA.

The lack of consideration of interaction between different activities, the simplicity of the activities considered and the expectation that a difficulty must be present the majority of the time all demonstrate how focused ESA is on static impairments such as sight loss, hearing loss or paralysis where limitation may be high and constant in a specific range of activities. In contrast, chronic illness can bring diffuse, moderate impairment in a large number and range of activities, but this is not captured well by ESA. These people may however be more disabled, as technology is less able to address such diffuse impairment, and because carrying out one activity often impacts another that superficially appears unrelated.

## **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.<sup>19</sup> However, most people felt so strongly that they cited several different aspects of ESA as of equal significance. 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:

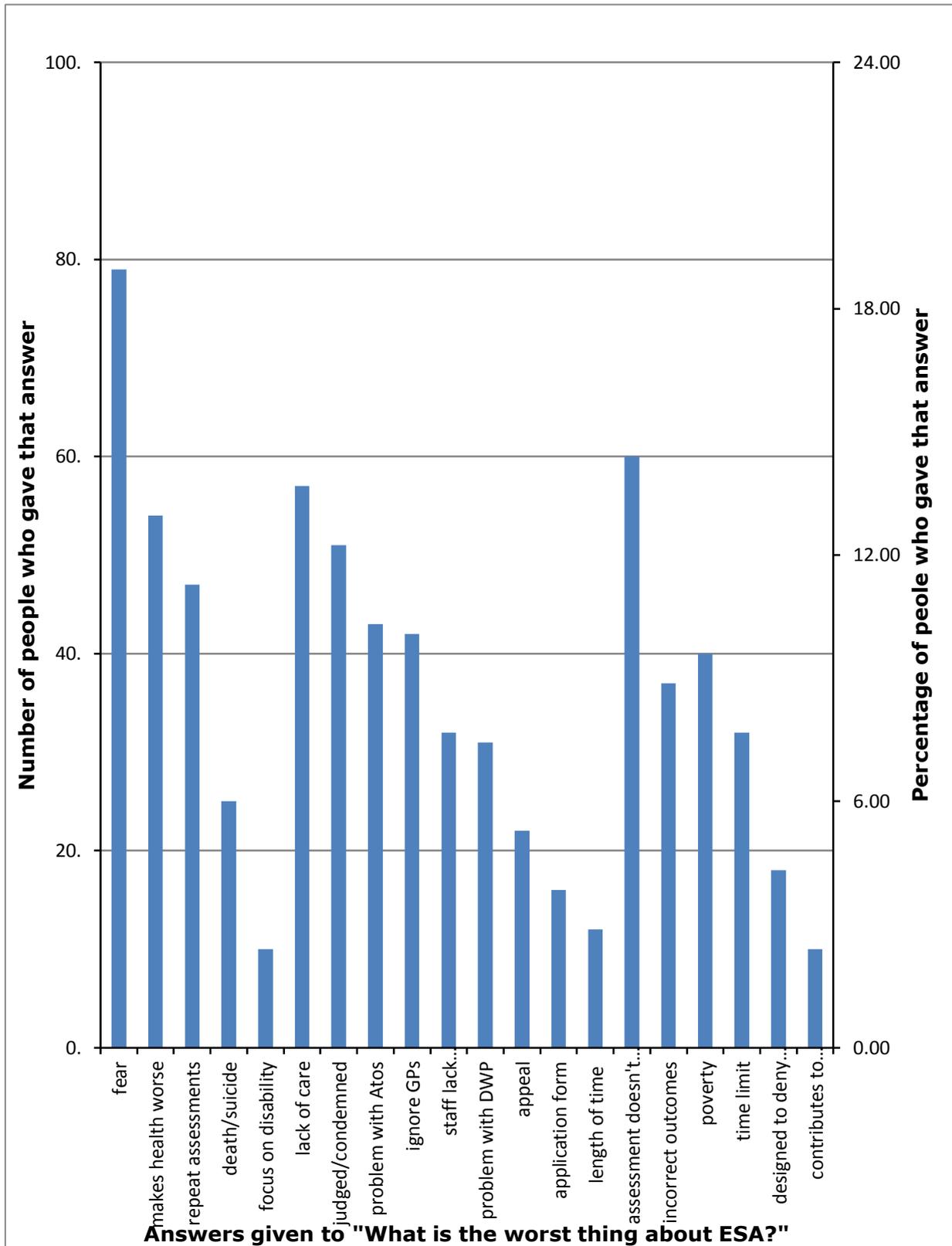
- The points system, descriptors and computer system are incapable of gathering the reality and complexity of people’s conditions;
- The descriptors do not capture a person’s state of health in a way that reflects their ability to work;
- Medical evidence from those who have detailed, accurate and relevant 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.

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<sup>19</sup> <http://diaryofabenefitscrounger.blogspot.co.uk/2013/03/esa-sos-starting-gun.html>

**Figure 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.<sup>20</sup> 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.<sup>21</sup>

*“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

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.<sup>22</sup> 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.”<sup>23</sup>

*“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*

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<sup>20</sup> CAB advice on ESA

<sup>21</sup> Disability Benefits Consortium, 2012

<sup>22</sup> Mark Hoban, Hansard: 19 Dec 2012, Column 784W

<sup>23</sup> Disability Benefits Consortium, 2012

*filling the form the same way every single time, the response can be totally different.”*

### **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 social security changes. Nine were cases where the family believe stress triggered the death; twenty where the person took their own life.<sup>24</sup> 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.”*

*“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, such as the commonly employed dichotomy between ‘workers/strivers’ and ‘shirkers/skivers’.

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

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<sup>24</sup> <http://calumslis.org/>

*“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 Feeling judged or condemned**

There is general support amongst the public for giving benefits to sick and disabled people.<sup>25</sup> However at the same time there is widespread belief that a high proportion of claims are not genuine.<sup>26</sup> 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 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.”<sup>27</sup> 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

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<sup>25</sup> British Social Attitudes Survey 30

<sup>26</sup> Survey for the Royal Statistical Society and King’s College London, as reported in Paige, 2013

<sup>27</sup> Grayling, Hansard, 11 Oct 2011 : Column 357W

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

relatively short training course thereafter [is] enough to ensure the assessments are medically accurate and fair?”<sup>28</sup>

The Royal College of Nurses was sufficiently concerned that it “refused to accredit the training of Atos nurse assessors” in 2009.<sup>29</sup>

*“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.<sup>30</sup>

A survey in August 2012 found that a strong majority – 85% - of welfare benefits advisers considered that Atos report accuracy had *not* improved.<sup>31</sup> 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.”<sup>32</sup>

*“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**

Dr. Margaret McCartney wrote in the British Medical Journal to question the ethics of allowing those without specialist knowledge to carry out assessments.<sup>33</sup> The Disability Benefits Consortium reported that “assessors’ knowledge and understanding of conditions, particularly mental health conditions, continues to be poor.”<sup>34</sup>

A survey of ESA claimants by the same group found that 66% felt the assessor did not understand their impairment or health condition.<sup>35</sup>

*“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.”*

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<sup>28</sup> McCartney, 2011

<sup>29</sup> Royal College of Nurses, 2010

<sup>30</sup> CAB, 2012

<sup>31</sup> Disability Benefits Consortium, 2012

<sup>32</sup> CAB, 2012

<sup>33</sup> McCartney, 2011

<sup>34</sup> Disability Benefits Consortium, 2011

<sup>35</sup> Disability Benefits Consortium, 2012

### 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. In the year up to May 2013, Atos requested evidence in 30% of cases;<sup>36</sup> fewer than 40% were returned within the two-week deadline and 71% were returned in total.<sup>37</sup>

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.<sup>38</sup> In a recent Spartacus survey, 88% of respondents thought medical evidence should always be included.

*"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."<sup>39</sup> 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. However, a recent DWP Research Report concluded that despite initial improvements, empowerment and autonomy of decision makers has since been lost.<sup>40</sup> 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."*

### 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

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<sup>36</sup> DWP. Fol request: statistics for DWP acting on Atos recommendations and medical evidence gathering. 2013.

<sup>37</sup> DWP. 2012. Employment and Support Allowance and the Work Capability Assessment. Oral and written evidence.

<sup>38</sup> Disability Benefits Consortium, *ibid.*

<sup>39</sup> Harrington, 2010

<sup>40</sup> Adams, Oldfield and Riley. 2012

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 is 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.<sup>41</sup>

*“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.<sup>42</sup> 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.<sup>43</sup> More recently, the DWP has had to halt all reassessments for two years in order to manage the backlog of cases waiting to be assessed.

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<sup>41</sup> Disability Benefits Consortium 2012

<sup>42</sup> E.g. Grayling, Hansard, 1 Mar 2012 : Column 425W

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

<sup>43</sup> 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>)

At time of publishing, Atos have now walked away from the contract to provide work capability assessments and no contractor has been found to replace them. Reassessments have also been paused in an attempt to address unacceptable and rising backlogs. However, these are temporary measures and are currently causing enormous uncertainty and further fear.

*“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.<sup>44</sup>

*“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 25% of those

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<sup>44</sup> Disability Benefits Consortium, 2012

found fit for work are in work 12-18 months later – in comparison, over three quarters of JSA claimants are in work 6 months after starting their claim.<sup>45</sup>

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.

*“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.”<sup>46</sup> This is exacerbated by lack of security over future retention of benefits.

People with disabilities are currently more likely to be affected by poverty. A report by the Joseph Rowntree Foundation showed that 24% of families with a disabled person were living in poverty in 2011-12,<sup>47</sup> and the Office for Disability Issues reports that disabled people earn less than colleagues without a disability.<sup>48</sup>

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

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<sup>45</sup> Barnes, et al., 2011

<sup>46</sup> Disability Benefits Consortium, 2012

<sup>47</sup> MacInnes et al., 2013

<sup>48</sup> DWP, Disability Equality Indicators: <http://odi.dwp.gov.uk/disability-statistics-and-research/disability-equality-indicators.php>

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.”<sup>49</sup>

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.”<sup>50</sup>

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, only working 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.”*

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<sup>49</sup> Grayling, Hansard, 3 May 2011 : Column 723W

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

<sup>50</sup> Miller, Hansard, 31 Jan 2011: Column 586W

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

# **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, 80% have not achieved success. Three were not implemented at all; nine 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.

Five recommendations were fully and successfully implemented.

- Include a personal justification in the ESA50 form;
- Include a personalised summary from the Atos assessor;
- Find out what happens to claimants after a decision has been made;
- Examine consistency between Atos assessors of different professions; and
- Monitor the implementation of recommendations.

Four recommendations initially met the above criteria, but further developments mean they must now be considered as ‘fully implemented but with limited success’:

- Make better use of the reconsideration process;
- Ask for recommendations on the mental, intellectual and cognitive descriptors;
- Examine the descriptors, particularly for fluctuating conditions and possibly for generalised pain; and
- Increase the role of the Decision Maker.

Five further recommendations were also 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 does not exist in a bubble and 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.

### **Assessment Methods**

Assessors need to have adequate knowledge. In **Australia**, the assessment process has been criticised because assessors could not have the depth of knowledge necessary to adequately assess any and all claimants.<sup>51</sup> The short time provided for assessments meant there was inadequate disclosure from claimants, resulting from a combination of lack of insight, lack of rapport with the assessor, and a tendency to want to “do their best” at interview.<sup>52</sup> Assessments were inconsistent, with different results arising from the same evidence.<sup>53</sup>

*“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.”*

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 [Decision Maker] in Centrelink [JobCentre] should make the initial assessment based on available information in the job seeker’s file. No face-to-face interview is required. Employment*

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<sup>51</sup> Finding Workable Solutions, 2008, cited in Nevile & Lohmann, 2011

<sup>52</sup> HREOC 2008, cited in *ibid*.

<sup>53</sup> Bendigo Access Employment 2008, cited in *ibid*.

*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.”*

In the **Netherlands**, assessment is carried out by a physician (not a nurse, physiotherapist or occupational health therapist) who is specialised in the employment area of the employee. Thus the assessor not only has more medical training than UK or Australian assessors (most of whom are not doctors) but also has specialisation in the relevant area of work.

The physician aims to find out from the claimant how he or she views the medical condition and what impact this has on function. Talking about daily experience is considered easier to access and describe<sup>54</sup> and can help show where a claimant’s activity level does not match their stated abilities.<sup>55</sup> “Clients who pretend to be ill are often not able to produce a consistently detailed account of their daily experiences.” However caution is important here as the experience of ESA claimants is that this has been taken too far, e.g. suggesting a person who can get around indoors can walk 200 metres – the experience of the authors of this report is that such an extrapolation is not true.

In **Norway**, assessment consists of a self-assessment form followed by a discussion with a supervisor, and any other information provided. The self-assessment form (Egenverduring) asks about goals and desires, experience and skills, home and daily life, health, personal strengths and weaknesses, and the support needed to work – i.e. it is a comprehensive assessment that covers more than just health and health-related function. It ends by asking the claimant to conclude whether they can work immediately, work in 6 months’ time given the right support, or cannot work in six months’ time. This is followed by a discussion with a supervisor (Ressursprofil) covering the same ground as the Egenverduring. This with other evidence such as GP evidence is then sent to the Norwegian Welfare and Labour Administration (NAV) for a decision. If needed the supervisor will then help to prepare a plan for reaching employment.

In **Denmark**,<sup>56</sup> access to support through rehabilitation or flexible jobs, or through early retirement or disability pensions, is given after a Resource Profile has been completed. The Profile is designed to be fully comprehensive, covering 11 areas of life besides health, in order to ensure that neither barriers to work nor resources to support work are over-looked. For some claimants this can be overly intrusive or irrelevant, although in theory caseworkers need not complete all parts of the Profile if certain areas are not relevant. Caseworkers would like social issues to be taken into greater consideration, rather than the current situation where they tend to be over-looked compared to health issues.

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<sup>54</sup> De Boer 1997

<sup>55</sup> Meershoek, 2012

<sup>56</sup> AMS, 2010

The Profile is meant to be composed in collaboration with the claimant, in contrast to the UK's Work Capability Assessment where the claimant does not see and rarely gets the opportunity to comment on the assessor's report. Space is deliberately given for the claimant to comment on what the caseworker has written, although in practice claimants feel wary of contradicting their caseworker.

The Profile was expected to be used to track claimants' progress but in practice it has not been used for this, being cumbersome, repetitive and unsuited to recording change over time. Caseworkers tend to use the Follow-Up Plan instead. The opportunity to record the claimant's resources, strengths and opportunities for development has also been under-used. This is largely because caseworkers fear that if they include such positive statements this may be inappropriately taken as evidence of the ability to work now. The Profile has therefore been used largely to record barriers, and most often health barriers, to work. Caseworkers are expected to make direct links to jobs when considering the claimant's ability to work. If a claimant is to be assessed as able to work, the municipality making that decision has to be able to specify the job role or function the claimant is able to do. In practice caseworkers do not often refer to jobs, generally when the caseworker considers the claimant to have such reduced capacity as to qualify for disability pension or early retirement.

In **Sweden**, individuals ill for more than three months are assigned a personal administrator to help with applying for and receiving sickness benefit. Sickness benefit is initially received on an own-occupation test and gradually extended to an all-work test over a period of 180 days. In total sickness benefit can only be received for two and a half years; after this people aged under 30 may receive activity compensation whilst those over 30 may receive sickness compensation. Activity compensation lasts for one to three years whilst sickness compensation lasts for three years.

Claimants are expected to have a mediation meeting within 90 days of starting sick leave. Before this can occur they have to have a SASSAM evaluation.<sup>57</sup> SASSAM is an abbreviation of "a formalised method for sick-leave investigation and rehabilitation." In a SASSAM meeting, the claimant meets with a supervisor to have a structured discussion of the claimant's abilities. The assessment is deliberately holistic, considering education, social factors and hobbies as well as health issues. As in Denmark, the assessment is expected to identify both resources for and barriers to work, covering both the individual and the individual's environment. The assessment is done with the claimant, and this participation is a fundamental part of the assessment method. The aim is for the claimant to take responsibility for their rehabilitation or move towards work.<sup>58</sup> The meeting identifies both reduced capacity for work and what support measures should be put in place to assist a return to work, such as rehabilitation (Försäkringskassan, 2010).<sup>59</sup>

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<sup>57</sup> Schenk, 2008 DRAFT

<sup>58</sup> Försäkringskassan, 2009

<sup>59</sup> Försäkringskassan, 2010

The SASSAM evaluation is followed by a mediation meeting. In these meetings, other agents such as the doctor, the employer or rehabilitation specialist are usually present as well as the assessor and the claimant. This meeting has been criticised as focused on the medical (individual) model.<sup>60</sup> The emphasis on framing the claimant as having an obligation to work if possible, which is also seen in the UK and Australia, is likely to reinforce the medical model that places the focus on the individual.<sup>61</sup> The mediation meetings have been portrayed as being about proving capacity for work, again the emphasis being on the claimant not on what society can do to make work possible for the claimant.<sup>62</sup>

In **Germany**, claimants can receive full benefit (if they are unable to work at least three hours a day) or partial benefit (if they can work at least three but no more than six hours a day). The ability to work is assessed against what the person can reasonably be expected to do. This is more than an own-occupation test but less than an all-work test because “the other occupation must be one that the person can reasonably be expected to accept, taking into account their training, their career so far and the social status they have achieved.” I.e., it does not include the ability health-wise to carry out work for which the person does not have suitable (transferable) skills, qualifications or experience.

## Employment Support

In several of these countries there are distinctions between sickness benefits, which may last a few years but no longer, and disability benefits, which do not generally involve an expectation of moving towards work. In this respect the UK may be considered to be ‘ahead’ of other countries. Nevertheless, the activation regime through JCP or the Work Programme fails to integrate 95% of people with disabilities or health conditions into employment.

In **Australia**, it is felt that services inappropriately assume a linear return to work, where “barriers to employment are progressively and permanently overcome.” There was a lack of recognition that successfully completing an initial training period does not remove the need for on-going support.<sup>63</sup> 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...*

*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*

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<sup>60</sup> Schenk, 2008 DRAFT

<sup>61</sup> Humpage, 2007

<sup>62</sup> Schenk, 2008 DRAFT

<sup>63</sup> Nevile & Lohmann, 2011

*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)."*

The emphasis on work is heavily criticised. Whilst Australia has a Social Inclusion Agenda and a Disability Services Standard, providers found a conflict between meeting these outcomes and meeting the job outcomes, which were the ones 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 the financial constraints. Consequently the provision of long-term support has decreased, and there is poor targeting of resources to the most disadvantaged.<sup>64 65</sup>

As in the UK, providers experienced difficulty with the compliance regime which was oriented towards a punitive method of ensuring engagement. This was considered to be contrary to the overall aim of supporting claimants and counter-productive to long-term trust-based relationships.

Australia used to have what was called a **Personal Support Programme** for the most disadvantaged jobseekers.<sup>66</sup> The PSP was introduced 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."

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."

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
- able to set personal goals

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<sup>64</sup> Nevile & Lohmann, *ibid.*

<sup>65</sup> de Koning, 2004

<sup>66</sup> Perkins, 2005

- better able to make decisions
- improved personal care
- increased feelings of self-worth
- increased ability to cope in stressful situations
- improved family relationships (FaCS 2002).

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

Unfortunately, PSP suffered from inadequate resources, lack of ongoing staff training specific to this client group, lack of integrated employment or community participation activities, lack of ongoing barrier-specific post-employment personal support, and a two-year restriction which meant that 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.”

In the **Netherlands**,<sup>67</sup> return-to-work support is provided by physicians in specialised employment agencies. The employee and employer are responsible for the first two years of sick leave, and the vocational rehabilitation offered includes “workplace assessment, worker training, case management, outplacement, career counselling, referral to specific training and training in job applications.”<sup>68</sup>

Claimants are encouraged to take initiative and to take responsibility for their plan to move towards work. The specific plan laid out is less important than the initiative of the claimant in devising the plan. This is also used to help lay the trend for the following consultations, as shown in this quote, “Clients who actively seek help and plan or think about returning to work in the future demonstrate the legitimacy of their complaints as well as their own trustworthiness. Physicians view their efforts as signs of good intentions and responsibility, and therefore as confirmation that their complaints are authentic.” However, this does not mean that lack of initiative means a person is to some extent over-exaggerating; on the contrary, it may signify a greater level of illness or other reduced capacity for taking responsibility.

Claimants who take such responsibility are often ‘rewarded’ by reduced recommendations, such as a longer period of sick leave. Even where claimants are less active in moving towards work, physicians tend to grant some leeway as long as there are some signs of progress. One physician is quoted as saying, “It doesn’t help to be strict. In such cases it’s important to support and coach clients. Otherwise you see them back on sick leave quite soon.” The aim is to build a relationship of trust, and sanctions and appeals against decisions tend to destroy this relationship.

There were concerns that when a claimant went to appeal against a physician’s decision, the claimant often wins not because the physician was wrong but because the specialists

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<sup>67</sup> Meershoek, 2012

<sup>68</sup> Dekkers-Sanchez et al., 2011

“have more prestige, so judges listen to them, not to us.” If such a concern is genuine then the UK would need to consider carefully how evidence from a medical expert balances against that of what might be termed an employment expert. Currently the UK experience suggests that employment experts (such as WCA assessors or Work Programme providers) are insufficiently expert and overly reliant on sanctions.

In **Norway** and **Denmark** the initial assessment is extended to consider what support the claimant needs in order to be able to work, and a personal plan is developed.

In **Sweden**, claimants under 30 who have run out of sickness benefit can receive activity compensation. The claimant’s personal officer helps the claimant to plan what to do during the time of receiving sickness benefit. This may be anything “from hobbies or sports to activities that are more vocational in nature. The main focus is on ensuring it includes activities that promote your health and well-being and that bring you closer to the labour market”.

Claimants receiving either activity or sickness compensation can try work or education for two years, with the compensation reinstated without reassessment during this time if a relapse occurs or work cannot be sustained. In the first year, 25% of the sickness compensation is kept tax-free.

In **Germany**, rehabilitation services are offered to people with reduced earning capacity. There is a ‘rehab first’ rule, meaning that claimants are expected to be assessed for rehabilitation before being assessed for disability pensions (BMAS). Claimants whose earning capacity can be restored or significantly improved by rehabilitation are expected to participate in this (Deutsche-Rentenversicherung).

## Payments by Results

Other countries have used payment-by-results forms of outsourcing to provide public employment services (PES). Examples include **Australia** since 1998 and the **Netherlands** since 2001.

Both countries have experienced problems with creaming and parking. (Helping the easiest candidates and leaving the others)<sup>69 70</sup> This is exacerbated by a lack of resources, which increases the need for risk selection.<sup>71</sup> Although the UK unemployment rate in 2009 was at the OECD average, its spending on active labour market programmes was less than half the OECD average.<sup>72</sup>

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<sup>69</sup> Struyven & Steurs, 2005

<sup>70</sup> de Koning, 2004

<sup>71</sup> Nevile & Lohmann, 2011

<sup>72</sup> OECD, 2010

There is little if any indication that more people have moved into employment as a consequence of the outsourced provision than would have occurred without it.<sup>73 74</sup> In Australia costs associated with PES decreased, but in the Netherlands they increased, so even for the same outcome it is not necessarily the case that greater efficiency will be achieved.<sup>75</sup>

Poor labour market conditions intensify the zero-sum nature of job outcomes and encourage employment support providers to focus on short-term aid only. The consequence is that jobseekers are not given training that will improve their job prospects in the long-term, when the job market picks up again.<sup>76</sup> Australia already provided little in the way of higher-level support: only 23% of jobseekers in the intensive support group received job-specific training, and most of this training was short-term. Over time, the level of service provided by Australian PES providers has decreased.<sup>77</sup>

The consequence of creaming and parking combined with a focus on short-term results is that the most disadvantaged become sidelined.<sup>78</sup> Concerns have also been raised over the loss of specialist provision for particular groups.<sup>79 80</sup>

To counter this, risk can be shared more equally between the purchaser (government) and provider by giving up-front payments, perhaps once certain conditions have been met such as an 'activity agreement' as in Australia.<sup>81</sup> Other options include payments for interim milestones and soft outcomes, and higher payments so that the provider has more financial room for providing employment support.<sup>82</sup>

## Recommendations

### Assessment

- An assessment of the ability to work should be based on more than health, and should include factors such as qualifications, experience and skills (which impact the type of work possible) and home life (which may present an additional drain on resources);
- Information should be gathered over a period of time, not just one interview, with a feedback mechanism between the person providing support and the person making the assessment which informs decisions about benefit eligibility;

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<sup>73</sup> Struyven & Steurs, 2005

<sup>74</sup> de Koning, 2004

<sup>75</sup> Struyven & Steurs, 2005

<sup>76</sup> de Koning, 2004

<sup>77</sup> Struyven & Steurs, 2005

<sup>78</sup> de Koning, 2004

<sup>79</sup> de Koning, *ibid.*

<sup>80</sup> Nevile & Lohmann, 2011

<sup>81</sup> Struyven & Steurs, 2005

<sup>82</sup> Nevile & Lohmann, 2011

- Assessment should occur as early as possible, particularly bearing in mind that individuals moving onto sickness benefits from work have already received 28 weeks of SSP;
- The assessor should be adequately specialised in the condition(s) experienced by the claimant, and at the very least should not be a generalist nurse or physiotherapist;

## **Employment Support**

- 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;
- Caseworkers must be adequately trained and equipped to provide support;
- Caseworkers must continue to work with claimants once they are in employment;
- Confrontations and sanctions should be avoided as long as possible, with an emphasis on trust and relational interaction instead;
- Claimants should be encouraged and supported to take initiative and responsibility; claimants who struggle to do this need extra support not sanctions;
- Intensive support and rehabilitation should be offered;
- Upfront fees and fees for intermediate milestones and soft-skills outcomes help to increase providers' capacity to assist claimants with intensive needs;
- Allow the claimant to choose their provider. Providers who are successful at placing claimants in jobs quickly gain a good reputation.

# An Alternative ESA and the Academic Evidence for Reform

## Alternative to ESA

This section aims to outline the "claimant journey" that we believe would ensure the best outcomes, both for the claimant and the taxpayer. It is followed by a section that looks at the existing academic evidence that led us to make those recommendations

**1. The person becomes too ill or too severely disabled to continue in work.** This would also include young people transitioning into adult support or finishing education who are unable to work.

**2. Statutory Sick Pay starts.** At this point, a range of holistic services aim to provide any support needed to stay in work - training, education, healthcare, reasonable adjustments, Access to Work, rehabilitation etc. We note that at present SSP is not always paid or not paid for long enough. The enforcement of SSP should be strengthened and more should be done to engage with employers at this stage to keep people in work wherever possible

**3. Statutory Sick Pay entitlement ends (28 weeks),** the person does not believe they can return to work and therefore makes a claim for Employment and Support Allowance.

**4. An ESA50 form is issued for the claimant to complete.** This must be simplified and redesigned to ensure that claimants can give the information required from them and know what that information is.

**5. An ESA113 is automatically sent to the claimants GP in all cases** (or the healthcare official that knows them best, as designated at initial claim request).

**6. GPs automatically consider at this stage whether, in their opinion, it would be a considerable risk for the claimant to continue with the process.** (Using sections 29 & 35 as discussed elsewhere.) If so, an automatic award is made and the process ends here.

**7. For all other claimants, early contact would be made (by a caseworker) to see what support might be initially offered**

**8. Over the next three months, the caseworker aims to meet or call the claimant on several occasions, at home, if necessary or desirable to the claimant.** At least once, this should be in the presence of other professionals involved with the claimant - perhaps a benefit advisor, community mental health practitioner, employer, physiotherapist or occupational health expert. This contact should take an inquisitorial approach, designed to elicit information, to build rapport and trust and to primarily assess barriers to work and how they might be overcome. A descriptor based system can never manage to accurately assess the full range of medical and social issues affecting ability to work.

**9. Wherever possible, the caseworker/assessor should have experience at least broadly relating to the impairment.** E.g. claimants with a mental health history should have a

caseworker specialised in providing mental health support, a claimant with a fluctuating condition should be assessed by a caseworker with training in this area.

**10. These initial meetings should also provide a range of support and information** on applying for applicable benefits to ease the transition, passporting to other benefits and schemes, education or training, advice on accessing healthcare or childcare and where appropriate signposting to more intensive support before work considerations can be made.

**11. At the end of this period, all collected evidence and information should be sent to an independent decision maker** who has training and experience both specific broadly to the type of disability and in occupational health. It might be that caseworkers also act as decision maker for the recommendations of their colleagues, thereby avoiding the necessity of two teams of trained and disability specific experts.

**12. The series of assessments should focus on barriers to work and how those might be overcome.** It would explore and offer a holistic range of support but would also consider "real world" factors such as availability of appropriate work, hours that could reasonably be worked and other home situations that may impact on the amount of work possible.

**13. An assessment might conclude that:**

A) A claimant might be ready to prepare for work (a subtle difference to being found fit for work) immediately with appropriate guidance and support.

B) A claimant might be ready to return to work in the near future, again with appropriate interventions, support and advice.

C) A claimant might be able to work at some point but are far from that presently.

D) A claimant might never be expected to carry out any kind of work at all.

E) A claimant will never manage work that is self-supporting but might benefit from a few hours work a day or work that is voluntary or not centered around a paid work outcome.

Those never expected to work should receive a higher rate to recognize the costs of living with a long-term impairment and that higher rate should also be available to those who commit to engaging with the new process and to overcoming barriers where possible.

**14. There is no benefit to making assessments exclusive or in denying support.** Where claimants currently suffer from considerable barriers to work, but don't qualify for ESA, under our system, they would be brought within the ESA process in order to receive the support and services they still need.

**15. If an assessment is made that the person will always face significant barriers to employment and that those barriers will only increase over time, then an entirely new system of support should be available.** It should assume that the claimant will always need more support from schemes such as salary supplements, incentives to employers and ongoing in-work-support, reasonable adjustments or Access to Work. Schemes suggested in later chapters such as flexible work banks, disability, self-employment, co-operatives or extra access to education or training should automatically be available whenever that person may need support.

**16. The transition between in work support and out of work benefits should be smoothed and simplified wherever possible, with unnecessary delays or "qualifying periods" removed,** allowing those same people to automatically re-qualify for social security within certain time-frames if they do attempt work, ensuring that pointless delays in reapplication or repeating complicated assessments forms is unnecessary.

**17. The caseworker should not end engagement when work is found.** On the contrary, it is vital that a good relationship is maintained wherever possible, that any in work issues can be smooth out quickly and easily and that any impending crises can be mitigated and supported.

**18. Reassessments may become unnecessary under this kind of co-produced, interactive system,** as support is ongoing and easily available. However, if reassessment does become necessary, this should be within reasonable timeframes to give the claimant time to "settle in" and to take the steps they have agreed are appropriate with their caseworker.

**19. Evidence suggests that sanctions and penalties are counterproductive, whereas incentives and encouragement tend to be more successful.** We recommend an additional "top up credit" for those four to be unable to work ever and for those who continue to engage positively with a caseworker where appropriate.

**20. If employment is assessed as being valuable, then every hour worked must count, allowing all contributions to be valued.** ESA must not be withdrawn the moment a claimant attempts work, but should be tapered off gradually as perhaps hours or confidence increase. For those that cannot manage self-supporting paid work, voluntary or caring contributions should be recognized and rewarded.

## **Academic Evidence**

Professor Harrington, then leader of the Independent Reviews of the WCA, suggested that organisations and individuals critical of ESA's current structure should also aim to provide alternative ideas and recommendations. In this section, we aim to do just that.

There is now substantial international and academic evidence to show what does and does not work when assessing and supporting disabled people. Unsurprisingly, ESA and the Work Programme fail in many of these areas, whether on providing valid assessments, or providing adequate and suitable support following the assessment.

The following section provides evidence from the academic literature on how the assessment process could be more effectively conducted.

## Early Intervention

Repeated studies show that the earlier an intervention occurs the less support is needed to return to work, the quicker that return is and the more sustainable it is.<sup>83 84</sup> In the Netherlands, assessment and support occur concurrently and start between two days and four weeks after starting sick leave.<sup>85</sup> With ESA this does not occur; there is a minimum period of 13 weeks before assessment and with high back-logs 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 a total of 9-12 months delay.

Both 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.<sup>86 87</sup> 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 that:

*“They expect you to pull yourself out of the swamp.”<sup>88</sup>*

This can result in GPs recommending longer periods of sick leave.<sup>89</sup> 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.<sup>90 91</sup>

We recommend that assessment for ESA occurs early on. If combined with the recommendation below for several meetings, the first assessment meeting could occur within one month of application. This is particularly relevant for people who have already had 28 weeks of sick leave.

## Role of GPs

In the UK there have been repeated calls for making GPs the assessor and decision maker for sickness benefits. This was backed up by a recent Spartacus survey which found that half of all respondents wanted either their GP or the doctor or medical professional who knows them best to be the one who carried out the assessment. However, this is not a role that

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<sup>83</sup> Franche, et al., 2005

<sup>84</sup> Hoefsmit, et al., 2012

<sup>85</sup> Meershoek, 2012

<sup>86</sup> Anema, et al., 2002

<sup>87</sup> Wright, 1997

<sup>88</sup> Dekkers-Sanchez, et al., 2010

<sup>89</sup> Engblom, et al., 2011

<sup>90</sup> Kuoppola & Lamminpää, 2008

<sup>91</sup> Wright, 1997

GPs either want or are qualified for. GPs more usually act as advocates for their patients, and to act as gatekeepers to the benefit system would conflict with this role.<sup>92 93</sup>

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.<sup>94</sup> 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."*

Similarly, the Work and Pensions Committee found that,

*"GPs and other healthcare professionals are likely to be best placed to provide detailed evidence regarding a claimant's capabilities."*

The input of a medical professional to confirm or refute a claimant's diagnoses, treatment and likely effects of these is vital. GP (or other suitably qualified and appropriate health care professional) input 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. In the same survey, 88% of respondents said medical evidence should always be included, with most of the rest saying it should be optional.

The suggestion from earlier sections that GPs also filter for unacceptable risk by considering existing regulations 29 and 35 in all initial cases, would introduce an important level of safeguard to the most vulnerable claimants.

We recommend that GP or other healthcare professional evidence be actively sought by the DWP in all cases.

## **Full assessment**

Support is most effective when the assessment and support offered actively consider non-medical factors alongside medical.<sup>95</sup> GPs may already naturally do this when deciding to give sick notes.<sup>96</sup> More information makes it easier to make an accurate assessment and then

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<sup>92</sup> Hussey, et al., 2003

<sup>93</sup> Wynne-Jones, et al., 2010

<sup>94</sup> Engblom, et al., 2011

<sup>95</sup> Dekkers-Sanchez, et al., 2013

<sup>96</sup> Krohne & Brage, 2008

provide appropriate support.<sup>97 98</sup> This would include information such as qualifications, experience and skills, and may include other information such as commuting costs, domestic responsibilities, childcare costs and caring duties.

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”.*<sup>99</sup>

In terms of employment disadvantage, people with severe disability and good education are not much more disadvantaged than mildly disabled people with good education; however people with severe disability and poor education are much more disadvantaged than those with mild disability and poor education.<sup>100</sup> For the same disability severity, the ability to work differs with the level of education – to treat the two as the same is to miss some of what makes up an individual’s capacity.

Some people face significant private barriers to work that may need to be addressed first, such as homelessness, substance abuse or recent release from prison. It is important that the ESA assessment and support process recognises when these issues exist on top of health conditions and is able to signpost to existing and appropriate intensive support schemes. As previously discussed, Australia used to have a Personal Support Programme for such people, to work on life issues before trying to address any work issues,<sup>101 102</sup> because this approach was considered more effective. 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.”*<sup>103</sup>

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 only of a series of activities, for which the ability to carry out the activity to varying levels results in various points being awarded. In

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<sup>97</sup> Dekkers-Sanchez, et al., 2011

<sup>98</sup> Dekkers-Sanchez, et al., 2013

<sup>99</sup> Dekkers-Sanchez, et al., 2010

<sup>100</sup> Berthoud, 2008

<sup>101</sup> Nevile & Lohmann, 2011

<sup>102</sup> Perkins, 2005

<sup>103</sup> Dekkers-Sanchez, et al., 2011

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.”*

Academic evidence suggests that assessment should consider all aspects of an individual's ability to work, because these interact with disability to result in different work capacities for the same type and severity of impairment. It is not unusual in OECD countries to deliberately consider the individual's capacity for work in relation to education, experience and skills as well as health.

## **Assessment Interview**

One-off meetings with an external assessor who uses an adversarial approach are likely to be inappropriate. 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.<sup>104</sup> This 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.”<sup>105</sup>*

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 the overall capability, particularly where repetition and reliability is an issue.

We recommend that assessments should therefore occur over several meetings to reduce the snapshot affect and to increase the amount of accurate evidence collected. This has

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<sup>104</sup> Nevile & Lohmann, 2011

<sup>105</sup> Nevile & Lohmann, *ibid.*

been recommended in Australia (Nevile & Lohmann, 2011),<sup>106</sup> and is already used in the Netherlands.<sup>107</sup>

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 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.<sup>108</sup> 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, always based around the barriers to work that exist. The Assessor should not have been exposed to bias regarding their role, nor be under suggestion or compulsion as to an outcome.

## **Relevant Experience**

It is strongly recommended that the assessor have experience in the relevant disability. Professor Harrington's first review showed that the qualification of the assessor negatively impacts the number of points awarded. A recent tribunal case ruled that the opinion of an assessing physiotherapist is not admissible as evidence of a claimant's mental health capabilities.

Australia has also experienced difficulties with assessors lacking experience in the condition of the person they are assessing.<sup>109</sup> In the Netherlands, the physician who carries out the assessment and support process is specialised in a particular industry.<sup>110</sup> The assessor may need to have more training than just general practice: GPs report more problems with assessing functional and work ability than do other type of physicians.<sup>111</sup>

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<sup>106</sup> Nevile & Lohmann, *ibid.*

<sup>107</sup> Meershoek, 2012

<sup>108</sup> Judge Hale, 2004

<sup>109</sup> Nevile & Lohmann, 2011

<sup>110</sup> Meershoek, 2012

<sup>111</sup> Lofgren, et al., 2007

We recommend that the assessor be specialised in the main health condition of the claimant and that in addition to that, occupational health training is standard for carrying out an assessor or caseworker role.

## Multi-disciplinary

Support from professionals in a range of fields, rather than just one, consistently increases the speed at which those off sick are able to return to work<sup>112</sup> and reduces the risk of long-term need for incapacity benefits or disability pensions.<sup>113</sup>

*“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.”<sup>114</sup>*

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.<sup>115</sup>

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.<sup>116</sup>

Multi-disciplinary would also include ensuring that the type of support offered or previously offered in Access to Work is made available to all disabled people. Currently it is only available to people in work, not those on benefits seeking work. It should be offered as an upfront, portable package to enable people applying for jobs to compete equally with other jobseekers. In this light, the decision to remove large parts of A2W (on the potentially flawed assumption that a prospective employer would purchase these items) is concerning.

In the UK, we recommend that a caseworker be able to liaise with the claimant’s healthcare and other involved professionals where appropriate. The caseworker should also assist with access to other benefits and work support such as DLA/PIP and Access to Work. Furthermore, as detailed below, it is vital that the UK invest properly in vocational rehabilitation.

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<sup>112</sup> Hoefsmits, et al., 2012

<sup>113</sup> Kuoppala & Lamminpää, 2008

<sup>114</sup> Dekkers-Sanchez, et al., 2011

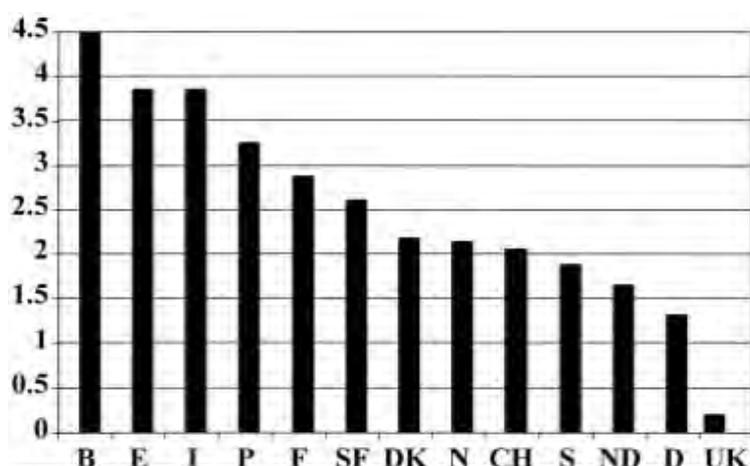
<sup>115</sup> Poulsen, et al., 2012

<sup>116</sup> Kuoppala & Lamminpää, 2008

## Access to treatment

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 without the other. This is particularly important for people with long-term conditions.<sup>117 118</sup>

However in the UK, people with long-term disabilities may suffer inadequate access not only to medical care, but also to vocational rehabilitation.<sup>119 120</sup> 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.



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).

## Disability Specific

Generic interventions aimed at all employees on sick leave, regardless of diagnosis, tend to be ineffective.<sup>121</sup> It is much more effective to tailor interventions, even just to broad physical/mental distinctions.<sup>122</sup> It may be that people with a visual impairment, for example, benefit from a different approach compared to people whose main problem is fatigue and the fluctuation in ability associated with chronic illness.

Both medicine and conservation have shifted away from intuition and experience to rely more on evidence of what does and does not work. In both fields, evidence has shown that

<sup>117</sup> Kuoppala & Lamminpää, 2008

<sup>118</sup> BSRM, 2000

<sup>119</sup> BSRM, *ibid.*

<sup>120</sup> Waldron, 2001

<sup>121</sup> Hoefsmit, et al., 2012

<sup>122</sup> Huijs, et al., 2012

some standard practice is not just wrong but even actively harmful.<sup>123</sup> Given the importance to disabled people that the support they are offered is effective, the UK should be seeking to build up a database of what works for whom. ‘Black box’ approaches may be less appropriate where best practice is not widely known and implemented.

Both assessment and support need to recognise that for many disabled people their impairment requires additional time and effort on a regular, daily basis. This is in both routine activities and in health maintenance.<sup>124</sup> A disabled person’s capacity for work is not just limited because of their disability (e.g. a deaf person cannot hear) but because in general they have less time for work once daily and health-related tasks have been completed.

We recommend that the DWP support evidence-gathering and data analysis to determine best practice. Once evidence is established, the DWP may wish to have guidelines to encourage this best practice.

## **Changing the Workplace**

Most policies to increase the employment rate of disabled people have focused on supply-side measures.<sup>125 126</sup> This amounts to a medical model approach, where the problem and its solution are located in the disabled person. The social model approach would focus on changing the work-place and other such barriers.

This might include making public transport both more widely available and more accessible or for instance extending free bus travel for elderly citizens to people with long term illnesses or disabilities; providing more childcare for parents with disabilities; enforcing the Equality Act 2010 requirements; and providing up-front changes such as assistive technology, accessible work-stations and lifts.

The current approach, with its focus on the responsibility of the disabled person, may mean that we fail UK to provide protection against poverty, market cycles, inequality and discrimination.<sup>127</sup>

We recommend that the DWP focus more on disabling barriers in the general environment as a means to improve the accessibility of work for disabled people.

## **Conditionality and Sanctions**

Sanctions reduce benefit receipt, but do not seem to improve the labour market position of those subject to sanctions.<sup>128</sup> They have “generally unfavourable effects on longer-term

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<sup>123</sup> Sutherland, 2008

<sup>124</sup> Barnes & Mercer, 2005

<sup>125</sup> OECD, 2003

<sup>126</sup> Barnes & Mercer, 2005

<sup>127</sup> Grover & Piggott, 2012

outcomes (earnings over time, child welfare, job quality) and spill-over effects (i.e. crime rates).”<sup>129</sup> Sanctions have a negative impact in that they result in people moving into temporary and low-paid work.<sup>130</sup> Sanctions may push people into the first available job, even if the job is not suitable.

We recommend that the DWP reconsiders the current balance of conditionality and sanctions in favour of a more supportive approach that is more likely to have long-term positive employment outcomes.

## Recommendations

An Alternative to ESA should follow these principles:

- Assessment and support should occur early on;
- Medical evidence should be obtained in all cases. It may be appropriate for the assessor or the DWP to take responsibility for obtaining this.
- Sections 29 and 35 of the regulations should be considered in all initial cases to filter for unacceptable risk.
- The assessment should take into account all holistic factors that may limit capacity for work, not just medical factors;
- The assessment interview may work better if conducted over several meetings, and if an inquisitorial rather than adversarial approach is used;
- The assessor should have the appropriate knowledge and experience to understand the impact of the claimant’s health condition(s) on his or her ability to work;
- Support should include professionals from a range of relevant fields and include access to social support, DLA/PIP, Access to Work and all other avenues of support that might be available, as these can all increase the capacity for work;
- There should be early and appropriate access to medical treatment and vocational rehabilitation for all people, whether currently employed or not;
- Support should be evidence based to ensure that all case workers know and utilise best practice;
- Support should recognise the additional effort and time that disability imposes on daily life, and that this necessarily limits the remaining time and energy for work compared to a non-disabled person.
- Support should include modifying the work-place as a pre-emptive measure, not just attempting to modify the employability of the disabled person. The DWP should put in place measures that increase the accessibility of work-places to disabled people as pre-emptive measures;
- Avoid the use of sanctions wherever possible. Focus instead on a more relational approach.

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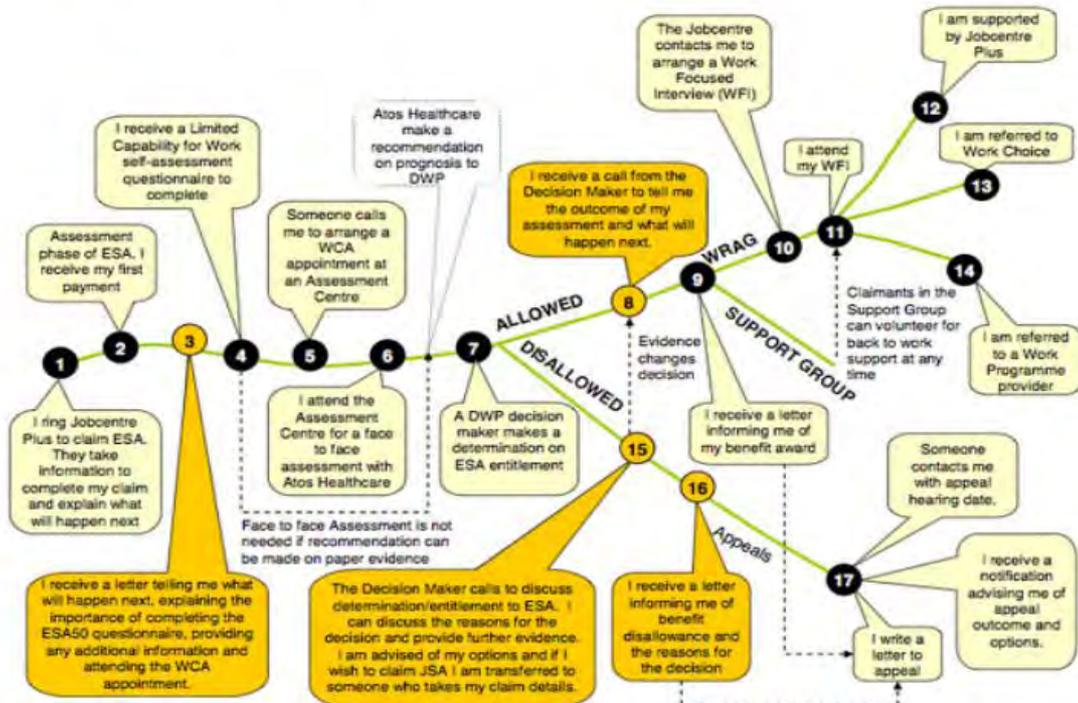
<sup>128</sup> Grover & Piggott, *ibid.*

<sup>129</sup> Griggs & Evans, 2010

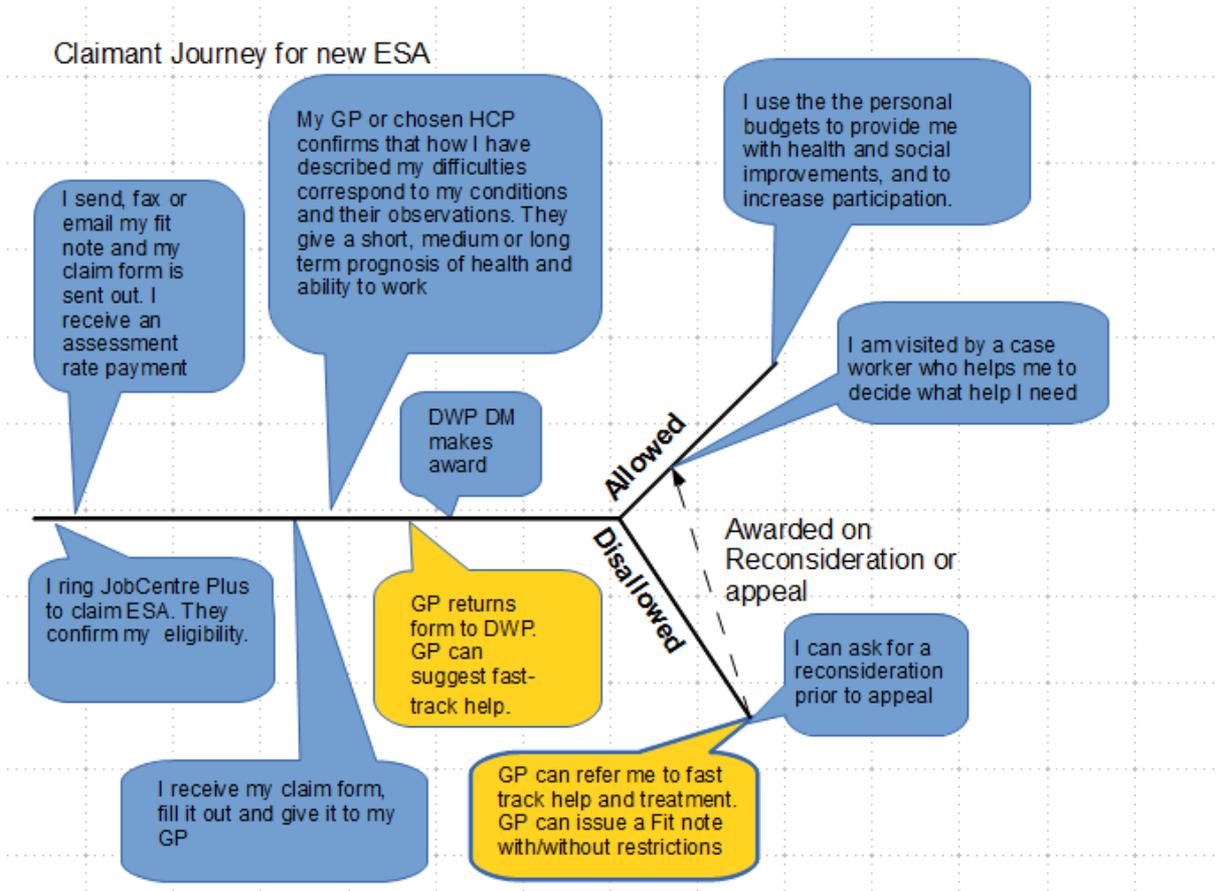
<sup>130</sup> Arni, et al., 2009

**Figure 2: Existing Claimant Journey for ESA**

Existing Claimant Journey for ESA



**Figure 3: Claimant Journey for New ESA**



## **Interim Recommendations**

In a further consultation in September 2013,<sup>131</sup> we asked people the question: ‘If you could say just one thing to Mark Hoban (then Minister for Employment), 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, the BMA and the RCGPs 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 28<sup>th</sup> 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 for work, 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*

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<sup>131</sup> <http://diaryofabenefitscrounger.blogspot.co.uk/2013/09/if-you-could-say-just-one-thing-to-mark.html>

*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.”*

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. Several respondents to a recent Spartacus survey for our submission to the Work and Pensions Committee told us that they had been refused JSA by the Jobcentre whilst waiting for their mandatory reconsideration of ESA.

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.<sup>132</sup> 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

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<sup>132</sup> 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>

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 whichever provider takes over the contract and the DWP as well as reducing delays caused by turning people away.

### **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.<sup>133</sup>

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 at least a minimum assessment period of 2 years for those in the WRAG and 3 years for those in the SG. This would bring the UK more in line with other OECD countries who award incapacity benefits for periods of 1-5 years.**

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.<sup>134</sup>

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<sup>133</sup> Response to WCA independent Review - Year 3 call for evidence, September 2012

<sup>134</sup> Harrington, 2011

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.

*“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.”<sup>135</sup>

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.”*

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<sup>135</sup> Grayling, Hansard, 10 October 2011 : Column 230W

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

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.<sup>136</sup>

**We recommend that this dichotomy is removed.**

## **6) Recording Assessments (H)**

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.<sup>137</sup>

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.**

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<sup>136</sup> <http://diaryofabenefitscrounger.blogspot.co.uk/2013/01/esasos.html>

<sup>137</sup> 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>

## 7) Evidence Based Review (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 ended their claim before a decision was made
- 25% who were found fit for work
- 9% who were awarded ESA WRAG
- 10% who were awarded ESA SG

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.

*"[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 appreciate the publication of the EBR findings in February. **However, we are concerned that information provided in an appendix appears to suggest that the 'expert panels' used were insufficiently expert. We are also concerned that the new descriptors were not sufficiently different from the flawed principles underlying the old descriptors, and therefore represent an insufficient improvement to the current system.**

## 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."<sup>138</sup> 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.

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<sup>138</sup> Harrington, 2012

*“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. GPs can also filter for unacceptable risk.

**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.**

## **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 further erodes the contributory principle from our social security system – penalising people who have worked and contributed tax and National Insurance.

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.**

## 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.<sup>139</sup> 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,<sup>140</sup> 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 a supply chain of specialist subcontractors at those with complex barriers.<sup>141</sup> 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.<sup>142</sup> 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 for those judged incapable of work, and granted unconditional support; and the Work Related Activity Group (WRAG) for people expected 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.<sup>143</sup>

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

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<sup>139</sup> DWP, 2006

<sup>140</sup> Freud, 2007.

<sup>141</sup> ERSA, 2012

<sup>142</sup> DWP, 2013; ERSA, 2013

<sup>143</sup> 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 December 2013 show that out of 235,070 attachments to the Work Programme from the three main ESA payment groups just 5.1% achieved a Job Outcome, that is employment sustained over at least 13 weeks.<sup>144</sup> The DWP estimated that **without intervention**, 16.5% of ESA claimants would find work by themselves within two years.<sup>145</sup>

The Job Outcome figure for the **long term sick or disabled**, i.e. those transferred onto ESA from previous Incapacity Benefit is **1.8%** 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.”*<sup>146</sup>

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.**<sup>147</sup>

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.**<sup>148</sup>

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.<sup>149</sup>

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.

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<sup>144</sup> DWP Tabulation Tool: <http://tabulation-tool.dwp.gov.uk/WorkProg/tabtool.html>

<sup>145</sup> ERSA Policy Briefing: the Work Programme, December 2012

<sup>146</sup> 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>

<sup>147</sup> Hayllar & Wood, 2011

<sup>148</sup> ERSA, 2013

<sup>149</sup> 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.<sup>150</sup>

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.<sup>151</sup> 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.

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<sup>150</sup> DWP, 2013d

<sup>151</sup> DWP, 2013b

*“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 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 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 Advisers<sup>152</sup>. 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.

*“At my first work focused 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.”<sup>153</sup>

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 on 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?”*

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<sup>152</sup> Work and Pensions Committee, 2013

<sup>153</sup> DWP (2013), *Work Programme Provider Guidance* <http://www.dwp.gov.uk/docs/wp-pg-chapter-3a-22-october-2012.pdf>

*“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 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.<sup>154</sup> 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*

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<sup>154</sup> Rees et al., 2013

*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”.*

**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 the 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.<sup>155</sup>**

**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**

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<sup>155</sup> See also: DRUK, 2013

**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.**

## 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 5% of ESA clients taking part in the Work Programme currently find sustained work of at least 13 weeks.<sup>156</sup> More move into work through their own efforts<sup>157</sup> and many return back to ESA, particularly if sanctioned from or otherwise removed from ESA before work is a realistic option.<sup>158</sup>

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% of new claims 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.<sup>159</sup>

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”;

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<sup>156</sup> Work Programme Statistics (Updated 13 November, 2013):  
<https://www.gov.uk/government/organisations/department-for-work-pensions/series/work-programme-statistics--2>

<sup>157</sup> Barnes, et al. 2011

<sup>158</sup> Adams et al., 2012

<sup>159</sup> Post, et al., 2006

- 3) Work does not exist that the claimant could do;
- 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 700 responses,<sup>160</sup> 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 flexible, available when and as the person is able to engage with it;
- 2) Working from home is increasingly achievable in the 21<sup>st</sup> century and many expressed a desire to work this way;
- 3) Training or further education could often help sick or disabled people either find or stay in work but is often unavailable 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, while the benefit system stifles progress;
- 5) Employers need to be engaged to a much 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, mental health 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 extreme 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.

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<sup>160</sup> 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 group 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.<sup>161</sup> 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.<sup>162</sup>

**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, and often pre-judge this cohort . 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 suggested 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*

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<sup>161</sup> See Gaffney, 2012

<sup>162</sup> See also DRUK, 2013

*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 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 being no better off - or even worse off - if they attempt work 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.”<sup>163</sup>

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.**

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<sup>163</sup> Fol 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](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/221274/foi-48-2011-permitted-work.pdf)

## 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 often 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 21<sup>st</sup> 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.<sup>164</sup> This kind of staged support offers a potentially viable model to support sick and disabled people attempting to start a business.**

**In Denmark, “Flex-Jobs” provide another possible solution for making sure that more sick and disabled people enter and remain in the job market**

*“Flex-jobs were introduced in 1998 as part of an attempt to reduce the inflow to the disability pension scheme. Flex-jobs are targeted at individuals with a permanently reduced working ability and intended as an alternative to disability pension. The flex-jobs are subsidised by a permanent wage subvention and may be in both the private and the public sector. Due to the reduced working ability of the target group, the number of hours and/or task assignments are reduced according to a specific agreement between the employer, the flex-jobber and the local municipality (the latter being responsible for administering the scheme). The municipal authorities reimburse the employer in the form of a wage subsidy corresponding to the reduction of the working ability of the individual (2/3 or 1/2 of the wages), while the person in the flex-jobs receive the full normal wage irrespective of weekly working hours. The municipalities also have a strong economic incentive to find flex-jobs for potential disability pensioners, since the reimbursement of from the central government is 50 % of the benefits for flex-jobs, and only 35 % for disability pension.”*

**Subsidising wages and employment in this way has proved popular and successful.**

**The government has 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**

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<sup>164</sup> See Casebourne & Coleman, 2012

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.

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 Allowance(s) are generally praised and users report a high level of support and provision of 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 judgmental 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.

*In light of this universal praise, it is with regret we note that the government announced on 7th April 2014 that it is cutting the support available through DSA. This is a retrograde step and particularly upsetting given that this, with the OU, is the only piece of social security and support for which disabled people had praise.*

**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.<sup>165</sup>

*“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 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.<sup>166</sup>

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<sup>165</sup> Carroll 2011, Parliamentary Briefing: Crohn's Disease

<sup>166</sup> Byrne, 2013

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.”*

## **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.<sup>167</sup> This might mean help with getting

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<sup>167</sup> NHS: Help for disabled parents: <http://www.nhs.uk/Livewell/Disability/Pages/help-for-disabled-parents.aspx>

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 billion<sup>168</sup> and £119 billion<sup>169</sup> a year, whilst voluntary work keeps the country functioning, safe and secure, often filling in gaps the state does not 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. Carers UK have reported that 44% of carers have been left in debt as a result of caring, while 36% struggle to afford utility bills, such as gas,

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<sup>168</sup> Carers Trust: Carers save the UK economy £87 billion a year: <http://www.carers.org/news/carers-save-uk-economy-%C2%A387-billion-year>

<sup>169</sup> Carers UK: Unpaid carers save £119 billion a year: <http://www.carersuk.org/newsroom/item/2121-unpaid-carers-save-%C2%A3119-billion-a-year>

electricity, water or telephone bills.<sup>170</sup> Moreover, 37% of carers believe their family is not adequately prepared to face an unexpected event.<sup>171</sup>

Any system that attempts to include a contributory element must recognise these contributions and acknowledge 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.**

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<sup>170</sup> Carers UK: ‘The State of Caring 2013’: <http://www.carersuk.org/policy-a-campaigns-scot/research-scotland/item/3440-the-state-of-caring-2013-scot>

<sup>171</sup> Centre for the Modern Family and Scottish Widows, ‘Families That Care’: [http://www.centreformodernfamily.com/Portals/0/Images/pdfs/SW\\_Report%203\\_V11.pdf](http://www.centreformodernfamily.com/Portals/0/Images/pdfs/SW_Report%203_V11.pdf)

## Conclusion

This report demonstrates the status quo presents an unforgiving environment for thousands of disabled people across the UK.

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.

This must change.

Few of the changes recommended in this report 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.<sup>172</sup> 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.

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<sup>172</sup> The preliminary estimated rate of fraud for IB in 2012/13 is just 0.3%. See DWP, 2013e.

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.

## **APPENDICES**

*These are available as \*.PDF files via the Spartacus Network website:*

Appendix A: Further Work –

[www.spartacusnetwork.org.uk/images/reports/AppendixFurtherWork.pdf](http://www.spartacusnetwork.org.uk/images/reports/AppendixFurtherWork.pdf)

Appendix B: Policy Assumptions –

[www.spartacusnetwork.org.uk/images/reports/AppendixPolicyAssumptions.pdf](http://www.spartacusnetwork.org.uk/images/reports/AppendixPolicyAssumptions.pdf)

Appendix C: Further Analysis of Harrington Progress –

[www.spartacusnetwork.org.uk/images/reports/HarringtonReport.pdf](http://www.spartacusnetwork.org.uk/images/reports/HarringtonReport.pdf)

Appendix D: The Employment Gap –

[www.spartacusnetwork.org.uk/images/reports/AppendixEmploymentGap.pdf](http://www.spartacusnetwork.org.uk/images/reports/AppendixEmploymentGap.pdf)

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