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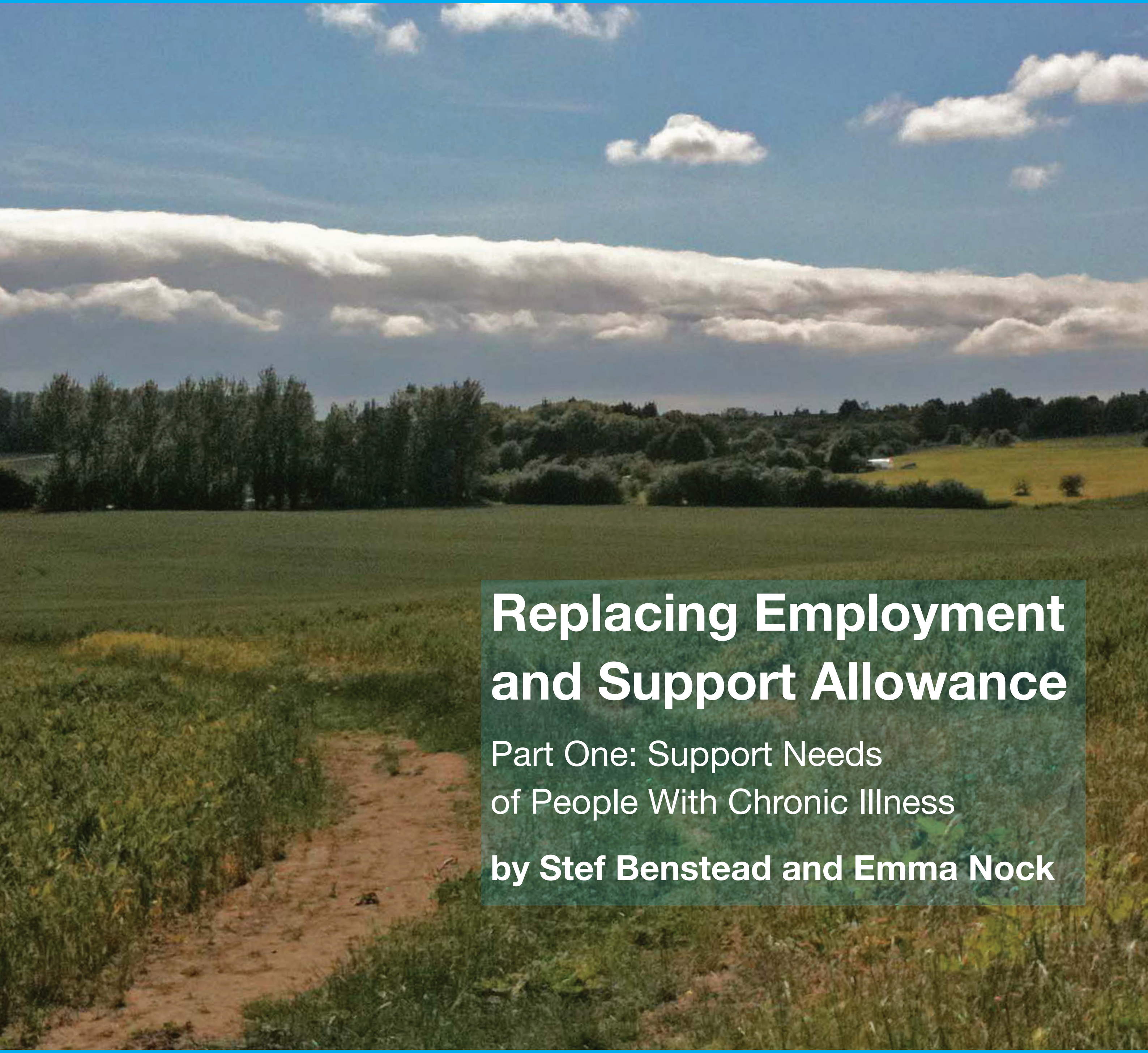

Replacing Employment and Support Allowance

Part One: Support Needs of People With Chronic Illness

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THE CENTRE FOR WELFARE REFORM

Contents

Abstract – **1**

Introduction – **2**

Chapter 1: Background Results – **4**

Chapter 2: Factors Affecting the Ability to Work – **8**

Chapter 3: Assessment Criteria and Support – **25**

Conclusion – **30**

References – **32**

Appendix – **35**

Abstract

This document is the first of a series of three reports looking cumulatively at the need to replace the Employment and Support Allowance with a proper system of assessment and support designed with and by people who have an illness, health condition or disability that makes it difficult or impossible to work. Extensive investigation, backed by our research, demonstrates that ESA and the accompanying Work Capability Assessment are not fit for purpose. This Ekklesia paper, researched by Stef Benstead and Emma Nock, and supported with funding from the St Joseph's Province Passionists' Grants Fund, looks in depth at the support needs of people with chronic illness, based on a detailed online survey in parallel with other research. The conclusion is clear: the government can provide the support needed for those with chronic illness to work, and then ask such people as are able to undertake that work; or it can reduce expenditure in that area and properly enable those with chronic illness to live lives that contribute to a good society in other ways, without conditions. But the government cannot have it both ways; it cannot refuse to pay the cost of employment support and simultaneously insist that individuals with chronic illness prepare for work that is simply not possible for them.

Introduction

Many countries across the developed world have been seeking ways to reduce the number of people receiving out-of-work benefits for health reasons (OECD 2003, 2010) in recent years. Countries have variously tightened eligibility criteria, reduced payments and increased support to help individuals prepare for and keep work (ibid.).

Compared to most other countries, the UK provides little in the way of vocational rehabilitation, is slow to respond to an individual becoming ill, gives little income with a high marginal tax rate and applies a tough conditionality regime (OECD, 2003). The UK tightened the eligibility criteria in 1995 with the introduction of Incapacity Benefit, and tightened them further in 2008 when Employment and Support Allowance was introduced to replace IB. Despite this, the UK has not substantially reduced the number of people claiming sickness benefits from a plateau of around 2.5 million, a level which was reached in the mid-1990s and not substantially changed since.

An increasing number of reports, case studies and stories attest to the failure of ESA. These come from many sources, including chronically ill and disabled people, grassroots disabled people's organisations (DPOs), local and national charities, MPs, political parties, peers, doctors and doctors' associations.

The list of failings is large and includes:

- A medical/functional rather than holistic assessment;
- Difficulty assessing mental health, fluctuating conditions and invisible conditions;
- Inability of the points-based descriptors to assess the risk of work on an individual's health;
- No clear evidence base of what it means to be capable of work, or the extent to which those found fit for work are capable of work;
- No clear evidence base for the criteria separating the Work-Related Activity Group (WRAG) and the Support Group (SG);
- No clear or consistent definition of work-related activity, or how the ability to carry this out can exist without the ability to work;
- Unsuitable requirements and sanctions for people deemed capable of 'work-related activity';
- A lengthy and complex yet poorly targeted assessment form;
- Not enough medical specialists to act as assessors; and
- Infrequent requests for medical evidence by the DWP, whilst claimants often have to pay for any evidence that they request themselves.

(Spartacus Network, 2014; Hale, 2014; Work and Pensions Committee, 2014)

The policy underpinning ESA is based upon assumptions that financial inequality is necessary to get people to work. This is similar to Douglas McGregor's Theory X of work motivation: that individuals lack a motivation to work outside of financial incentives. The assumption of poor work ethics amongst the unemployed has been a central principle of social security policy for decades (Alcock, 2003; Byrne, 2005; Fraser, 2009;

Shildrick, et al., 2012). In contrast, Theory Y posits that individuals are motivated by the fulfilment of working and satisfaction from earning one's own income. Theory Y is supported by academic evidence, which shows that the commitment to work is strong and enduring, even when the work is low quality or damaging to health (Kemp and Davidson, 2010; Kirsh, et al., 2012; Shildrick, et al., 2012).

There is a growing call for a fundamentally new assessment, founded on evidence-based assumptions, best practice seen in other OECD countries and the advice of those with lived experience of chronically disabling illness (Spartacus Network, 2014; Litchfield, 2014; Work and Pensions Committee, 2014). Often this refers to a more holistic assessment, as is seen in countries outside the neo-liberal/Anglophone grouping, for example Scandinavian countries, the Netherlands and Germany. Many of these countries also provide substantially more support for people with chronic illness than does the UK.

Despite these calls, the government is cutting the support available to those in the WRA group, whilst increasing the conditionality imposed. This is being done without consideration of disabled people's needs and in direct conflict with published reports on the WRA group (Hale, 2014) and the impact of such a cut in financial support (Low, et al., 2015). The government has also expressed concern about an alleged over-use of regulations 29 & 35 (regulations that allow people to be found unfit for work if work would cause their health to deteriorate), despite the importance of these regulations to many who otherwise could be put at risk.

There are two groups of people who might be expected to be best placed to comment on what capacity for work looks like and means. These are disabled and chronically ill people themselves, who know what they can and cannot do and what support they need, and employers, who know what they can routinely provide in the way of in-work support and what is beyond their scope or affordability. When designing an assessment process, the views of sick and disabled people are the most important. The views of employers can then help to refine this, by identifying additional people who are likely to struggle not because they are unable to work at all but because employers do not have the knowledge and/or financial capacity to provide the necessary support.

Ekklesia commissioned this research in order to contribute to the debate on what the assessment criteria and process should look like, by asking chronically ill people to contribute their views on what information should be included, how decisions should be made and who should be making them. This report presents the results on support needs from Ekklesia's survey. Details of the results can be found in the Appendix.

The next stage in this research is to run a consultation on a proposed new system. Using data from our questions on possible assessment methods, we have developed an initial proposal for a new benefit and assessment method. This proposal will be put out as to consultation with a wider range of disabled people, including those with physical impairments, learning disabilities and other conditions that are less likely to be called a chronic illness. The final report in this series will present a new assessment and support system, based on the findings presented in this report, in the consultation document and in response to the consultation. This work was commissioned by Ekklesia and funded by the St Joseph's Province Passionists' Grants Fund.

Chapter 1: Background Results

1.1 Methods

The lead author, Stef Benstead, wrote the first draft of the survey based on her prior knowledge acquired from the academic literature, other published reports, previous survey experience including design and analysis, and discussions with other chronically ill or disabled people.

The first draft was sent to members of the Spartacus Network for comments and improvement. These were incorporated and the second draft was discussed with a representative from New Approach. The improvements suggested by New Approach were made and the third draft was sent to other grass-root DPOs for feedback and suggestions. Most suggestions were included in the final draft.

The survey was published online on 21st September 2015 and ran to 31st January 2015. It was also made available to download as Word, PDF or OpenDocument, and there was the option to email or post completed surveys to Ekklesia. The survey was promoted on social media, particularly on Twitter but also on Facebook, and the grass-roots DPOs were asked to promote the survey to their members.

An easy-read version was made available on 17th December as a Word document and as an online form.

The text-based responses were analysed using content analysis, carried out by Emma Nock. This was done by reading all the responses three times before reading through again and highlighting the main themes. A fifth read-through was used to divide the main themes into sub-themes. The themes and sub-themes were then entered into a spreadsheet and a final check carried out to ensure consistency and reduce the likelihood of any omission errors. Stef Benstead looked at a random selection of 20 responses for each question and discussed these with Emma Nock to check consistency and thoroughness. No comments were left unrecorded; all were counted in a suitable sub-theme even if it were the only comment in that sub-theme.

1.2 Survey Responses

The survey received 291 responses over the period from 1st October 2015 – 31st January 2016. Not every individual responded to every question, and in particular the text-based questions had fewer respondents, typically around 150. Three people left the survey after question nine (an option to leave and return later was provided after question eight) Sixteen people had dropped out of the survey after question 17 (again, the option to leave and return later had been given here), rising to 31 by the end of the survey.

The majority of questionnaires were completed online and the survey was promoted via social media. Consequently, those who do not use social media and/or who struggle to use a computer are likely to have been excluded from this study. This means that the results cannot be assumed to be representative of the overall population of chronically ill people. However, there was little significant and no material difference in the answers based on age (over or under 50), gender (male and female) or ESA status (in the ESA Support Group or not on ESA and not applied in the past year). The results compare well with previous surveys (e.g. Hale 2014, Low et al. 2015) and can be taken as indicative of disabled people's views. From this, it seems unlikely that other surveys, with a larger respondent base or including those not using computers and social media, would return results that lead to substantially different conclusions.

Where differences did occur, it was between people in the Support Group of ESA and people not on ESA. People in the Support Group were less likely to consider that having several meetings with an assessor, and always having a face-to-face rather than paper-based assessment, would be beneficial, compared to people not on ESA. This seems reasonable given that people in the Support Group are likely, on average, to have severer conditions that may be less ambiguous and therefore do not need as a deep an assessment to reach an appropriate decision.

Most of the figures reported in the main body of this report refer to answers from tick-box (Likert scale and multiple choice) questions. The results from the text based responses confirm those from the tick-box questions. Some questions included similar answers, and the survey shows that similar responses were gained: for example, delays in getting treatment or not being able to get suitable treatment were common themes across the questions. Further details on the results, including tables, can be found in the appendix. Quotations from respondents are shown in green speech bubbles.

This survey focuses on people with chronic disabling illness. An appropriate assessment process and best-practice employment support may differ for people with sensory impairment, learning difficulties, autism spectrum disorders and static disabilities such as paralysis and limb amputation. It would be helpful to build on the results from this survey by putting the proposed new system out to consultation for people of all impairment and illness types, in order to modify and fine-tune the proposal as appropriate. In particular this would help with suggestions for contentious areas such as who should carry out assessments and what activity, if any, it is reasonable to ask people with limited capacity for work to do.

1.3 Background Data

The respondents to the survey were predominantly female (70%) and over forty (73%) with 40% in the 51-60 age bracket alone. In contrast, most ESA recipients are male (53%) and a smaller proportion is over 45 (57%; ESA data is in 10-year age brackets). When looking just at those on ESA, either Support Group or WRAG, 64% are over 45. This means our respondents were typically older and more likely to be female than the typical ESA claimant. However, age and gender had little to no impact on the results and conclusions, so this difference seems unlikely to have resulted in biased results (see the appendix for more details).

Over half of the respondents were in the Support Group of ESA (52%), whilst one quarter were not on ESA at all (24%). This was a surprising result, given that the target audience was people with chronic illness that limits the capacity for work. However, this group still reported significant difficulties with work arising from health problems, albeit less frequently than did respondents in the Support Group. It may be that these people have a partner or other source of income and so do not need to claim ESA, or that a previous application was unsuccessful and the individual has not applied again.

14.5% of our respondents were in the WRAG. Of the rest, two were found fit for work and did not appeal (0.7%) whilst eight are appealing a FFW decision (2.8%). 10 were waiting for a decision (3.5%), and seven were on Incapacity Benefit or Income Support (2.4%).

Physical health problems (83%) were more common than mental health problems (60%). There was an overlap between the two, with 71% of people with mental health problems also having physical health problems, and 51% of those with physical health problems also experiencing mental health problems (i.e., 42.5% had both). A small number also reported problems such as learning disabilities or an autism spectrum disorder (8.5%; all with a mental health and/or physical health problem as well).

Over half have not worked for at least five years (55%), whilst a fifth left work between one and five years ago (21%). Some people (6.6%) have never worked; this group was on average younger than the rest of the respondents, with an average age of 31. Some of the respondents were in full-time work at the time of the survey (5% working over 35 hours per week; 3.1% working 26-35 hours per week) whilst others did a small amount of work (4.3% worked up to 15 hours per week) or worked part-time hours (2.7% worked 16-25 hours/week). Whilst a large proportion were not in any paid work, even part-time (85%), 55% of respondents were engaged in some form of activity whether paid work (55%), studying or voluntary work (40%) or caring duties (30%). For most people, this was less than fifteen hours per week.

1.4 Attitudes Towards People With Chronic Illness

Respondents identified several areas of concern with the current system. There was a strong feeling among some respondents that claimants were treated as being irresponsible or less than human during the assessment process. This was the case in several areas, including the assessment process (assessors and decision makers), employment support (JobCentre and Work Programme), politicians and policy makers, and the general public. Additionally, respondents said that the current system was overly suspicious, assuming a high rate of fraud and setting out to deliberately cut the number of successful claims.

> The claimant should be treated like a sentient human being instead of a lying scrounger.

> Treating those with disability as rather stupid and recalcitrant unemployed people is not only unfair but potentially losing resource for the country - those with disabilities may be educated and able but with specific impairments where adjustments are available.

> Let me say categorically that I am disgusted with the way disability assessments are conducted and that attitude is transmitted down into employers. We are all human beings and deserve to be respected physically and more importantly emotionally/mentally. I am happy to have recently left the UK permanently.

In contrast to language that describes benefit claimants as work-shy and unmotivated, the evidence is that claimants retain a strong work ethic even as their experience of work continues to be that it is low wage, attracting limited benefits, insecure and damaging to health (Shildrick, et al., 2012; Kirsh, et al., 2012; Kemp and Davidson, 2010). Work is considered desirable because it provides an earned income, not charity, and the desire to earn one's own income is strong. People need neither a reduction in out-of-work benefits nor an increase in in-work benefits to incentivise them to work; work has enough value in and of itself. The commitment to work is tenacious.

> Stop the demonisation of the sick and have a complete process that accepts that people need help either financially or more practically. Make this help available and don't just pay lip service.

> Not being able to work has had a devastating impact on my life. I worked since I was 17 and had finally found a job I really really loved.

Whilst many of the respondents have been out of work for significant periods of time, most still contribute to and engage with society in other more accessible ways, such as studying, volunteering and caring duties. Free-text responses confirmed that many respondents have a strong commitment to work, even where work is not possible or makes their health worse.

Language that refers to strivers versus skivers, shirkers and scroungers is inappropriate in this context. It cannot be assumed that people with chronic disabling illness are not contributing to society, simply because they do not contribute through paid work, or contribute only a small amount by this means. Where individuals do not contribute through paid work, many feel guilty and upset about this. People who cannot work for health reasons should be supported financially to participate in life, but the current system instead asks for too much activity from the claimant, causing harm to health (Hale, 2014).

Key Point:

1. Individuals contribute to society in a number of ways other than paid work, and the value of these contributions should be recognised.

Chapter 2: Factors Affecting the Ability to Work

This chapter looks at the survey responses to questions dealing with the capacity for work. These include questions on what factors led to leaving work, what makes finding and keeping work difficult, and what support would be necessary in order to make work possible.

2.1 Health Problems

For many respondents, the problems they experience are those common to what are often termed fluctuating, variable or invisible conditions. These include pain, fatigue, and unpredictable capacity for work. The difficulties that these cause can make standard forms of work impossible; these people need to be able to work in small amounts at random times.

These were not mild problems for many. More than half reported severe or fairly severe difficulties[1] with work due to pain (60%), fatigue (76.5%; 56% with severe fatigue) or poor concentration (67%) arising directly from the health condition. The side-effects of medication can cause the same problems, with over two in five respondents experiencing severe or fairly severe difficulties with work due to pain, fatigue and concentration arising from the side-effects of medication.

It was felt that the WCA as it stands cannot capture these issues well. The points-based nature of the WCA means that conditions that cause diffuse effects across the majority of activities are poorly treated compared to those that cause very specific effects on particular activities. Yet these are not minor issues for our respondents, they are key to their reduced capacity for work. It is imperative that these issues be fully and properly considered in any assessment of capacity for work. Given the way that ESA is formulated, it is unlikely that adding a descriptor to the current WCA (as was trialled in the Evidence-Based review) can successfully capture the extent of the impact that these symptoms have on the ability to work.

2.1.1 Mental Health Conditions

For individuals with mental health conditions, depression and anxiety can have a major impact. Although these are common conditions and many people do work whilst

> The problem with the current tests are that they are superficial. For example the assessor told me he was going to say a number between 1 and 10 whilst standing behind me and judge my hearing, based on that! Audiology reports from my hospital were not sought.

> More consideration of cognitive impairment. Asking someone to add up two numbers in an assessment is not a good indicator.

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[1] Unless stated otherwise, all figures in this section are for the percentage of respondents reporting severe or fairly severe difficulties with work arising from a particular symptom.

> More emphasis should be placed on mobility - at the moment, the inability to plan a journey seems to ranked higher than the inability to actually go on one.

suffering from them, they also exist in severe enough forms as to make work impossible or very difficult. In our survey, 52% reported severe or fairly severe difficulties with work arising from anxiety. Individuals may also struggle with social interaction (42%); this could be due to depression, anxiety or a social phobia, or even due to a physical condition causing cognitive fatigue. Other difficulties commonly given by our respondents include coping with change (46%), coping with being in a workplace (57%) and emotionally challenging work (48%). All of these may be expected to cause significant difficulty with working.

> After trying to cope with anxiety and depression for a number of years by just keeping on keeping on, without ever quite recognising the nature or extent of the problem, I came to a kind of crisis where I wasn't able to concentrate or function at all. It was several months at least before I began to have some perspective on what had happened.

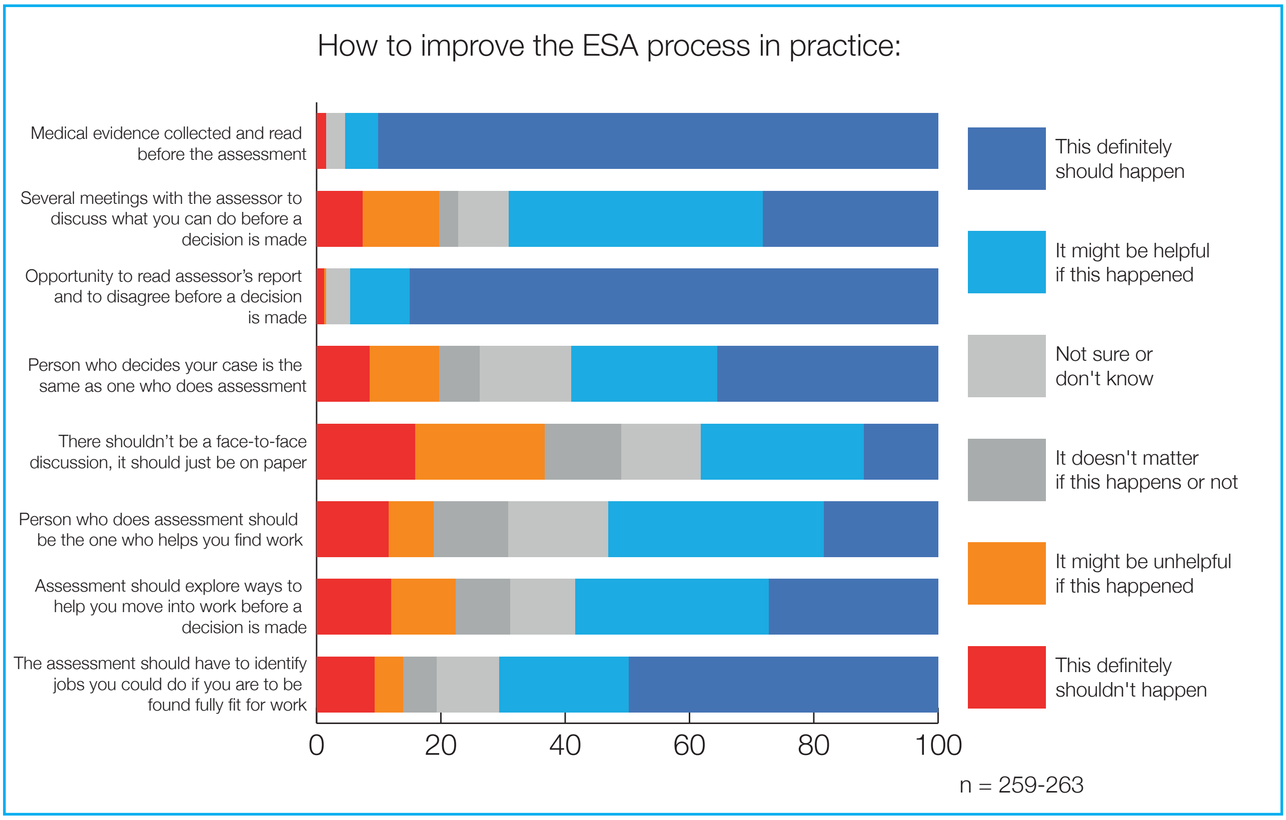
> Being mentally ill is hard. Depression and anxiety make it hard to wake up. It's hard to motivate myself. Socially acceptable self needs are not met for instance I forget to eat, drink and shower. It's okay though because I'm in WRAG and apparently somewhat fit to work.

2.1.2 Cumulative Problems

Many respondents experienced problems with sitting or standing, even for half-an-hour, and with moving around (58%) and using their hands and arms (42%). Respondents particularly reported struggling with work that requires walking (49%) or physical effort (56.5%). Again, the side effects of medicine can also have significant impacts on these areas. The result is that it is difficult to carry out work that involves moving around (such as nursing, or manual trades) but also difficult to remain at a workstation for reasonable lengths of time.

ESA does not always give adequate weight to the cumulative impact of struggling with multiple activities, such as the impact of pain and fatigue on a wide range of physical activities. Indeed, ESA was specifically designed to make it more difficult (relative to Incapacity Benefit) to be assessed as unfit for work based on the accumulation of points across activities; low-scoring descriptors from IB were taken out in the design of ESA. Yet this accumulation of difficulties is arguably more debilitating than scoring highly on a restricted range of activities, because it is less amenable to improvement through the use of aids and adaptations.

Cognitive impairment arising from chronic illness is a major part of generalised pain and fatigue, with 67% reporting that they struggle to concentrate or think clearly. Such ‘brainfog’ is not included in the WCA at all; the descriptors in the WCA are designed for mental health conditions, learning disabilities and autism spectrum disorders. Thus they exclude cognitive deficit arising from an otherwise physical health



condition, such as Ehlers-Danlos Syndrome, Postural Tachycardia Syndrome and Myalgic Encephalomyelitis. Yet these symptoms are generally intractable to treatment and unhelped by any physical aids, adaptions or adjustments (Raj, 2006). Thus they

> DWP does not understand my disability (I do not think they understand the occupational impact of reduced manual dexterity or of any condition involving chronic fatigue).

> Using hands to move or grip things (or type more than 1-fingered) for an hour guarantees useless hands next day due to pain.

> Some of the questions are daft. For example most people can do a button up. I've been in intensive care and been able to do a button up, doesn't really mean I can work though does it?

> Most importantly the points based system should be scrapped. Doctors do not treat people based on how many points their illness scores and it is completely immoral and wrong to assess people's fitness to work with a score sheet.

> The questions about epilepsy were based entirely on what I am able to do whilst I'm not having a fit, rather than what I can do whilst I'm having a fit and there was absolutely no understanding of the fact that the most disabling thing about my condition isn't what I can't do but what I daren't do.

can represent more of a barrier to work than physical weakness or fatigue.

2.1.3 Variable Working Capacity

Individuals may struggle to finish a project or task (48%), meet deadlines or to work at the same pace as healthy, able-bodied colleagues (57%). They may need regular time off, such as for medical appointments (53%), but also irregular, unpredictable time off to cope with flare-ups (68% report severe difficulties). At work, an individual may need scheduled rest breaks (61%), or become suddenly unable to continue working (66%), for example due to an epileptic fit.

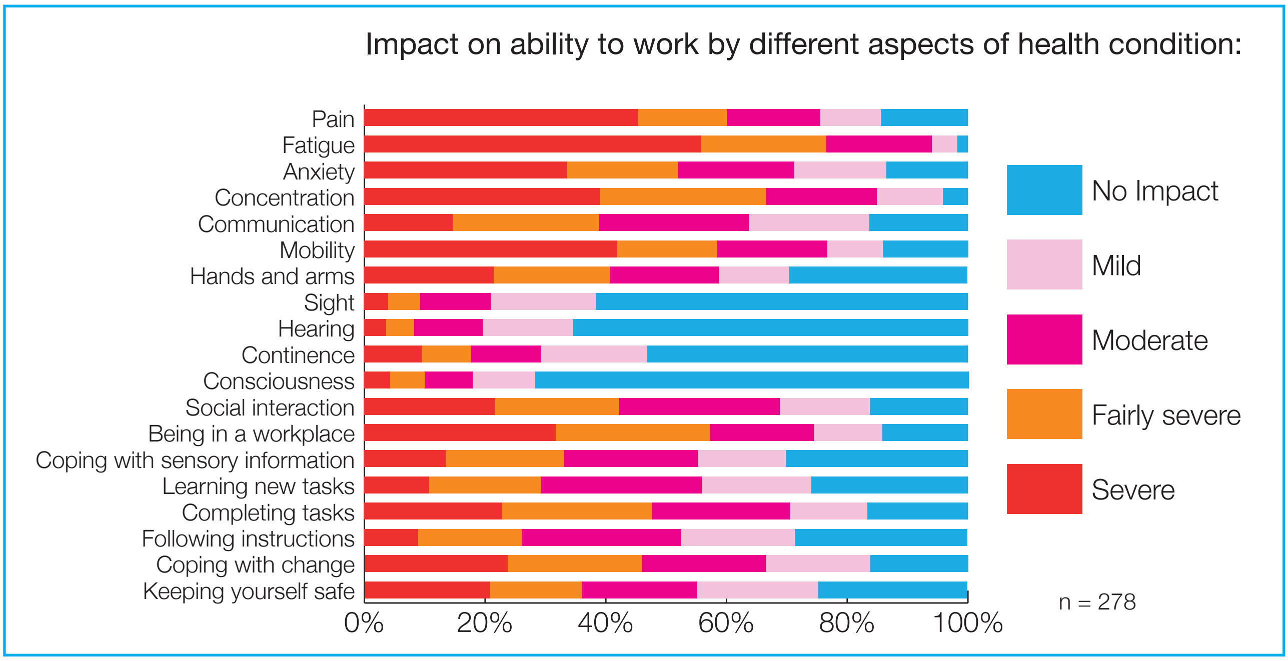
People who were not on ESA were less likely than those in the Support Group to say that they can't work at the same pace as other people (46% vs 57%), that they need unpredictable breaks from work (51% vs 70%) or that they need scheduled breaks during work (57% vs 78.5%). However, these still presented problems for a substantial proportion of this 'less ill' group, suggesting that an individual's benefit status (i.e., not being on ESA) is not an adequate indicator of their capacity for work. Those on ESA are likely to have very limited capacity for work, but it does not follow that everyone with limited capacity for work is on ESA. This is likely to be partly due to individuals not claiming ESA if they can live off another source of income, such as a partner's income, but may also be where individuals with significant health problems have been assessed as fit for work and have not subsequently re-applied. This possibility is supported by evidence from employment support providers that they frequently receive claimants who have been refused ESA yet are demonstrably unfit for work (Work and Pensions Committee, 2013).

> I have no idea day to day, or even within a day, how my health will impact on my ability to do simple tasks let alone more challenging ones. I can be too ill for weeks or months or absolutely normal for a week or two.

It is apparent from this that many of our respondents struggle to compete in an open labour market because the combination of lower working speeds and both predicted and unpredicted time off (due to their health condition) means that they cannot complete tasks as quickly and efficiently as other employees. From an employer's perspective, such an individual brings extra costs associated with workflow and HR management, and reduced gains due to less work being completed relative to what is normal for the contracted hours.

2.1.4 Limited Capacity For Work

When considering what work respondents could do, almost half said they could not work at all, even if all appropriate support were provided. Over half say that the variation in the symptoms (52%) and in their severity (56%) causes severe difficulties for work. The risk of making health worse also causes severe difficulties for the majority of people (59%). Including the figures for 'fairly severe' difficulties brought these figures to 80% or more. People who were not on ESA were less likely than those in the Support Group to say that work makes their health worse (44% vs 68.5%), although it was still a significant problem for more than two in five of those not claiming ESA.



These results suggest that for at least some people, work is so far from being a panacea that it is more likely to cause harm than good.

Other research supports the above conclusion that work can make health worse (MacDonald, et al., 2012), as has also been shown for work-related activity (Hale, 2014). Attending work whilst ill makes subsequent sickness absence more likely, suggesting that work prolongs and/or worsens an illness (Ashby and Mahdon, 2010). For a substantial proportion of people with work-limiting chronic illness, work is a hazard to their health.

When individuals do return to work, it is usually because health has improved; conversely, poor health remains an overriding barrier to work (Cordon and Nice, 2006; Kemp and Davidson, 2010). Other research has confirmed that health problems can both limit access to work, and make keeping work more difficult (Shildrick, et al., 2012). It has also been established that poor quality work is at least as bad as, and possibly worse than, the health effects of being unemployed (Waddell & Burton, 2006; Butterworth, et al., 2011; Baumberg, 2011). Sir Michael Marmot concluded in his 2010 review that, “Jobs that are insecure, low paid and fail to protect employees from stress and danger make people ill” (Marmot, 2010). All of this means that we should be very careful when asking those with long-term illnesses to work, to ensure that we do not prolong or worsen their illness.

2.1.5 Impact of Chronic Illness on Capacity for Work

These responses are all consistent with what is expected from the fatigue and pain associated with many physical illnesses, as well as the symptoms experienced by those with mental illnesses. The Work Capability Assessment does not do well at taking these problems into account, either from the point of view of the claimant or that of the employer. An adequate assessment needs to factor in the impact on the claimant’s health of trying to work whilst ill, and the impact on the employer of having someone who needs frequent time off on both a regular (such as for medical appointments) and irregular (such as due to a flare-up) basis. An assessment that

> I am in so much pain and discomfort on waking that I am unable to move for several hours until my painkillers kick in. I don't see how I can obtain and retain employment with the myriad of problems I face on a daily basis - but, I do feel guilty about this and worry about my future - especially on benefits and am petrified that I will be forced into work I simply cannot do.

> I wouldn't be able to work even with support. I think we have to accept that sometimes, with the best will in the world, people are just too poorly.

focused on an individual's labour market competitiveness might better serve both chronically sick people and employers (OECD 2010).

When our respondents were asked about the importance of issues that are currently not well covered by the WCA, over 80% said that it was very important that consideration be given to pain (84%), fatigue (85%), and poor concentration (83%). The free text responses indicated a number of additional areas that are thought to be poorly assessed by the WCA. The main conditions identified were mental health, chronic illness, and fluctuating conditions as well as pain and fatigue. Respondents wanted a more holistic assessment and felt that the current tick box approach and tasks chosen as descriptors were inappropriate.

Following on from this, respondents indicated that the need for unexpected breaks whilst at work (82%) or time away from work (81%) should be considered during an assessment of capacity for work. Over 60% also wanted the ability to work under pressure (65% and to deadlines (64%) to be considered, as well as the impact of anticipated time off work, such as for rest breaks (62%) or medical appointments (69%) while 79.5% considered that the impact of psychological distress was also very important to an assessment of capacity for work.

> Combination of fatigue, memory problems & pain which are all unpredictable became too much to cope with as working was making things worse. Employer was as helpful as possible, including coming with me to Jobcentre to explain the extent of the problems I was having with part-time work. Employer, JC+ & myself decided it wasn't sustainable after a few months' trying.

The assessment therefore needs to take much greater account of the impact of pain, fatigue, cognitive difficulties, psychological distress and both predicted and unpredicted time away from work. There is a difference between an individual being 'capable' of work (which could include working for small units of time at irregular intervals, spread out over a longer period), and an individual being employable in a labour market that demands efficiency (and therefore needs regular, assigned working hours).

Key Points:

2. A range of areas not well captured by the WCA are key to the understanding and assessment of capacity for work. These include mental health, varying or unpredictable capacity for work, and the accumulation of incapacity from multiple origins.

3. The social security system needs to protect those whose health and quality of life is at risk of being damaged by requirements to engage in work or work-related activity.

4. The decision of capacity for work should include labour market competitiveness.

5. The assessment should consider the overall capacity for work, including the need to work at a slower pace or have breaks from work, rather than focussing on isolated activities.

2.2 Issues Outside of the Workplace

2.2.1 Health and Social Care

A common theme throughout the questions was the need for both better and faster healthcare, as has been reported elsewhere (Low, et al., 2015; Cordon and Nice, 2006; Anema, et al., 2002; Wright, 1997; Kuoppala and Lamminpää, 2008). A number of questions addressed this issue, asking about difficulties experienced now or in the past; what support would be necessary to find work and to maintain work; and the extent to which delays or inadequate treatment impact the ability to work. Less than 13% reported that they have always been able to access appropriate or timely healthcare, whilst over half report that they continue to have difficulties. The need for adequate and timely healthcare was also brought up in the text-based responses.

> First of all I would need to get some treatment for my mental health condition. I haven't had any treatment for my Borderline Personality Disorder. Nothing. Zero. I don't meet the criteria for treatment. If I committed a crime I would meet the criteria . . . There's little to no point in discussing anything else as I have no idea if my support needs would change after treatment.

> I have ME/CFS and my energy levels were too low and general malaise too severe to continue working, even part-time, and even with my employers being very flexible and helpful. I struggled to cope with energy, flu-like symptoms and gut symptoms every day I worked and had to take approx a week off a month because working made all my symptoms so much worse.

> I have ME which has continuously deteriorated over more than 30 years, mainly because the NHS is not interested in properly investigating people with chronic conditions that don't have a very obvious cause. If we try very hard to insist on service from the NHS we are branded as hypochondriacs and given even less service--or even struck off altogether.

Previous employment programmes for people with chronic illness, such as Pathways to Work, have done well when they have included the NHS, albeit they were aimed

> Delays in my 'treatment' have meant I have gone past the point of 'treatment' being effective.

only at those with moderate, not severe, conditions (Lindsay, et al., 2008). For many it seems that a lack of adequate healthcare is holding them back from being able to work, because it is also prolonging their illness. Delays in healthcare can make illnesses worse or less tractable to treatment (Wang, et al., 2004).

It may be worthwhile to consider how underfunding of the health service impacts on sickness rates in this country, and the knock-on effects to employment. Cuts to social care may also have an impact, as there has been an increase in death rates from 2011 onwards (following a decrease year-on-year since 1970) for which the cuts to social care have been implicated (HSJ, 2016). Increasing people's capacity for work may therefore require an increase in funding to both health and social care.

2.2.2 Home Life

Respondents clearly felt that a range of factors were important when considering an individual's ability to work, not just functional limitations as assessed in the Work Capability Assessment. Many areas of life are affected by chronic illness, and these areas need to be considered as part of an overall assessment of capacity for work (Meershoek, 2012; Dekkers-Sanchez, et al., 2013). It is no use to assess someone as able to work, when the effort required to do so would leave them unable to maintain personal hygiene, or to cook and wash up; or when they would become unable to provide safe and adequate care for dependent relations (Barnes & Mercer, 2005; Dekkers-Sanchez, et al., 2010).

> The main thing is that the person with the condition should be central with services working round them; health, work and benefits plus housing and transport should be working together in centres for working-age people.

> The main thing is that the person with the condition should be central with services working round them; health, work and benefits plus housing and transport should be working together in centres for working-age people.

> Tolerance, patience and an understanding of how my illness affects me DAILY as well as at work.

Respondents considered that the need for help with personal care (58%), home responsibilities (66%), and caring responsibilities (62%) should be included when assessing an individual's capacity for work.

2.2.3 Availability of Jobs

Respondents also felt that the availability of jobs locally should be considered (61%). For example, it might be appropriate to consider the impact of longer commutes on health and remaining capacity for work for those who live in rural or more deprived areas, where jobs are on average further away; 62% said that the impact of commuting caused them difficulty with work, and 54% that its impact should be included in an assessment of capacity for work.

The quality of jobs is also important, as both poverty and cycling between low pay and no pay has negative consequences for those otherwise in good health (Shildrick, et al., 2012); for people already in poor health, job quality may be even more important if a move into work is to be sustained.

The current welfare-to-work approach is supply-side driven, focusing on attributes of the work-force such as timeliness and motivation (Casebourne and Coleman, 2012; Trotter, 2013). At the same time, there has been market failure at the lower end of the job market: loose regulation means that employers can have loose hire and fire policies, and consequently see little value in investing in their employees; employees cannot afford to invest in training themselves; and risk-averse governments are more focused on rapid results than sustainable and long-term benefits (ibid.). What is needed at this point is innovative investment like Working Rite, which supports 16 to19 year-olds and prospective employers to take on apprenticeships, and green jobs such as renewable fuels and recycling schemes (Casebourne and Coleman, 2012).

> In the past, employers turned me down because either I was overqualified and they thought I wouldn't fit into the team, or they said I wouldn't fit into the team because they couldn't adapt their ways of working.

Key Points:

6. Capacity for work is impacted by the provision of support in areas of life outside of the individual workplace. These can include health care, personal assistance, home help, caring responsibilities, commuting and regulation of the labour market to promote more and better quality jobs.

7. People with chronic illness need a wide range of support if they are to be able to work.

8. People with chronic illness may benefit from re-training, particularly where re-training may allow the individual to use remaining health capacity better or compensate for loss of capacity in a previously trained area.

9. The assessment should give direct consideration to the skills that the individual has and whether or not these can be used given the claimant's health condition.

2.3 Skills

A relatively small proportion of respondents indicated that a lack of recent job-applicable skills was holding them back from finding work (21%). A much more significant difficulty was caused by having skills, but being unable to use them due to their health condition; for example, if a person was engaged in a manual trade which pain or fatigue now renders impossible. 63% reported that their health problems meant they could not continue in their previous line of work. In such a situation, a person may be unlikely to find a new job without retraining into a different area, as their previous skills and experience are not transferable: employers report that redeploying an employee from manual labour to desk-based jobs is “unworkable” (Sainsbury and Davidson, 2006). This may render some disabled people effectively unskilled or low-skilled relative to the job market, compounding the low skills that already exist amongst the disabled population (Berthoud, 2006; Meager, et al., 1998).

On the other hand, individuals could be unable to get higher level jobs due to the impact of their illness, whilst being over-qualified for lower-level jobs. These people would benefit from employers offering flexible working patterns, including reduced or unpredictable hours. The government may need to provide practical and financial support if employers are to be able to do this.

An assessment should consider both what skills and experience an individual has, and how his or her condition affects the ability to use previous experience and what this means for job applications (i.e., whether the person has skills or experience in the areas of work for which they still have capacity; 78%).

> The jobcentre Disability Employment Adviser told me I was unemployable due to my combined physical and hearing impairments and the fact I was a graduate.

2.4 Employers

2.4.1 Employers’ Attitudes

Respondents commonly felt that employers would be reluctant to employ someone with a long-term illness, due to the employers’ attitudes towards people with long-term illness or disability. Respondents thought that employers are fearful of employing people with chronic illness (63%) and discriminate against such people (59%). Respondents expected that employers would be concerned about any associated cost (66%; e.g. to cover sick leave) and a belief that people with long-term illness are less productive (58%).

> In the past, employers in the fields of my skills and experience have rarely offered part time hours, and any such jobs were always so desirable that there was strong competition, so why would an employer take someone like me with a work history full of gaps, and limited experience, trying to get their foot on the career ladder over someone with a much more solid work history and much more experience? If I tried to take simpler jobs, which were sometimes offered part-time, I was overqualified (because I had A-levels!!!).

Respondents earlier had indicated that they typically feel they cannot work at the same pace as healthy people, and that they struggle to work under pressure and to

> *I can work and am qualified to do so I apply and don't even get an interview. This includes Local Government.*

> An understanding employer who will look past the gap in the CV and the period of illness. It is rare to get past the initial application.

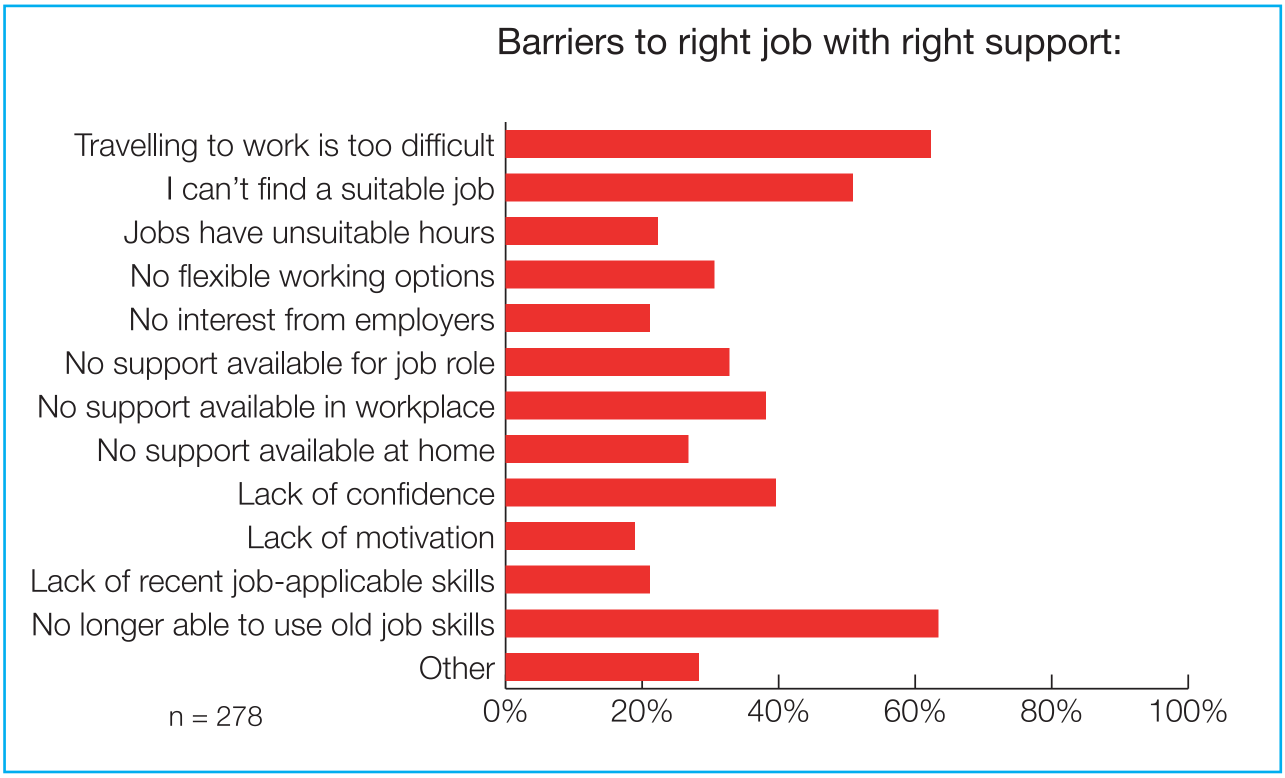
> The inconsistency of my illness makes it difficult to keep a steady job. I take on work when I feel well enough but usually relapse within months and have to leave... Employers often do not understand and it is not possible for me to just work when I am well as I need a consistent income and employers need staff they can rely on.

meet deadlines. They also reported a need for frequent absences, either planned or unplanned, from work. In these respects, if employers do view those with long-term illness in the way that respondents believe them to, the employers may be correct to do so. It could therefore be unreasonable to expect employers to take on such individuals without some form of assistance from the government to redress any labour market disadvantage, and unreasonable to expect the individuals concerned to find and keep work in the current competitive labour market.

> The discrimination and bullying I received from my previous employers is what made me mentally ill.

Over 50% said that they experienced a lot or quite a lot of difficulty due to employers not combating bullying and harassment from colleagues or managers (64%). Many reported that in order to be able to work, they would need both a supportive employers (71.5%) and supportive colleagues (64%).

> I suffer from severe blackouts, I was pushed out of my last job due to them. I didn't leave, I was simply denied hours until I had no option but to quit.



2.4.2 Flexible Working

Work was more likely to be possible when it was flexible (71%), from home (65%) and more similar to a commissioned outcomes system than the standard model of work. However, the definition of flexibility used by our respondents is not the same as that used by employers and neo-liberal politics. In the latter two, flexibility means a transfer of risk from the employer to the employee, where the employer can easily change wages (usually downwards), hours (also downwards) and job role (Standing, 2011). Flexible hours, as offered by employers, usually means non-standard yet fixed hours; for example, hours that fit in with school hours and childcare arrangements, rather than 9–5.

In contrast, what those with chronic ill-health need is the option to work at their pace (not the employer's), their time (which may vary considerably from day-to-day) and their chosen role, and with adequate income both in terms of amount and stability. This generally works out as meaning working at random hours for random lengths of time, depending on the moment-to-moment capacity. For an employer, this would mean entirely unpredictable amounts of work being performed, greater likelihood of an employee missing deadlines, and increased costs associated with managing unpredictable workflow. For this reason, secure jobs like these are not common in the labour market, and may often depend on an employer wanting a specific skill that a disabled person has that is worth the risks and costs associated with such flexible working.

As part of such flexible working, some respondents also indicated a need for paid disability leave (53%), Disability leave, in contrast to sick leave, would be paid from the first day or part-day of leave, and would be at 100% of the wage or salary. This would provide the employee with income stability and remove the financial pressures associated with sick leave. However, for this not to represent an additional cost to the employer of taking on a chronically ill or disabled staff member, the government would have to be responsible for paying disability leave, at least for employees who join a company with a disability or chronic illness.

> I would need to find an employer whom is flexible with how the work can be done i.e. working from home when needed and different hours of the day if need be but there will be times even if this were possible I would have periods of feeling to unwell to even work from home due to the nature of my condition.

Some respondents indicated that they would be better able to work if they had relaxed disciplinary procedures (44%); again this would form part of what chronically ill people mean when they speak of flexible working. Disciplinary procedures currently mean that an individual can lose their job or be subject to additional measures if they have recurrent sick leave. The symptoms experienced by many of the respondents

> The worst part is that everything is so variable so there is absolutely no work that I can say I can do reliably and in a timely manner. Some days I can do something with no problem at all and the next be completely incapable of even comprehending what needs doing.

to this survey (such as fluctuating symptoms and ability, pain, fatigue and cognitive function) are likely to cause recurrent capability issues. For these people to be able to sustain employment, it is necessary that they are protected against dismissal on capability grounds; at the same time, for the employer to be able to employ such a person, the employer is likely to need some measure of compensation to cover the cost of reduced or fluctuating workflow.

It seems appropriate that people who struggle in this way, whilst having some capacity for work, should be classed as unable to work due to their inability to work in the open labour market. Self-employment and piecemeal or temporary work are not adequate substitutes, due to their precarious nature; the dependence of many disabled people on this type of work is a significant contributor to the employment gap (Berthoud, 2006; Metcalf, 2009). Individuals with chronic illness need a secure, stable income, which is not achievable when any capacity for work is not itself stable.

> Once I went back to work after being signed off with work related stress (caused by them not making allowances for my physical ill health) and then undergoing an operation which had resulted in two weeks in hospital, a week of which was in ICU, they made me work a year with no paid sick leave and then made me redundant. By the time I left I was just so relieved as I was completely exhausted both physically and mentally.

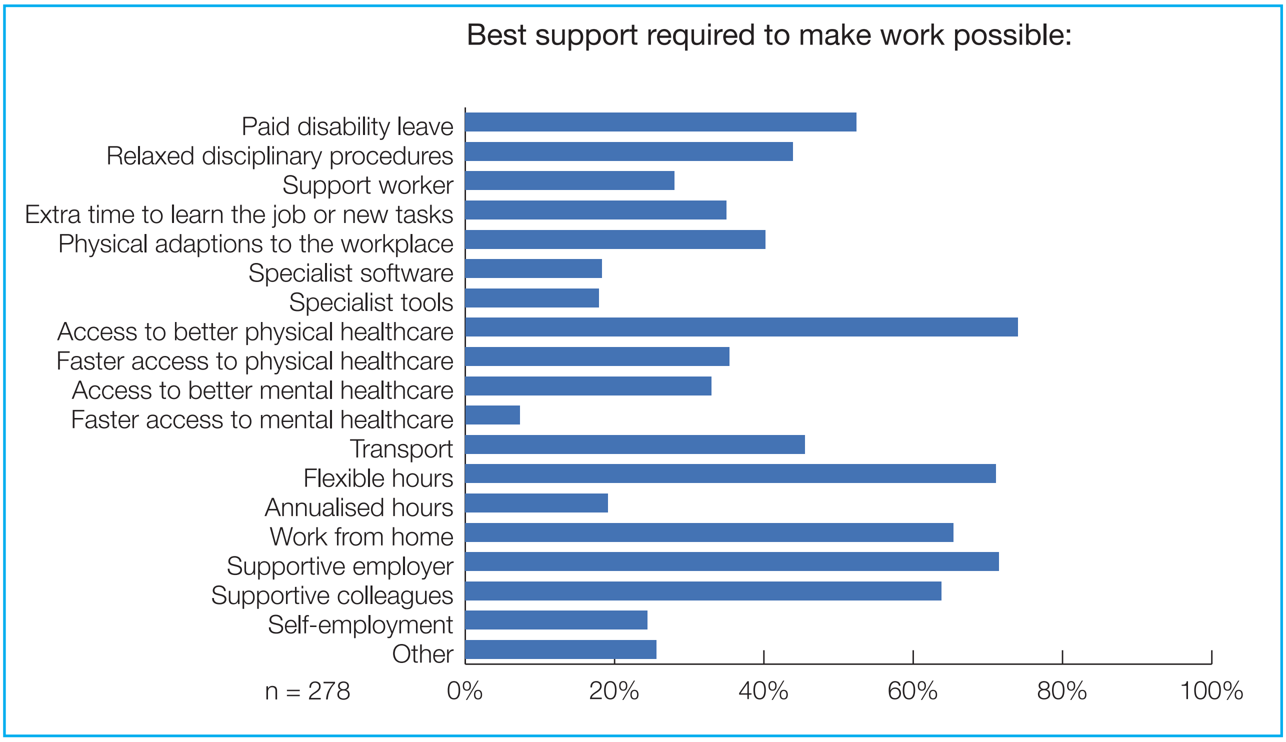
2.4.3 Reasonable Adjustments

General physical adaptations were wanted by 40% of respondents, with specialist software and tools coming in at 18%. These 'reasonable adjustments', perhaps what are most commonly thought of by employers and policy makers, are in reality seen as less important by our respondents than adequate healthcare, flexible hours and supportive employers. There is only so much that can be done with physical adaptations for people who may be better considered as 'ill' than 'disabled'.

> Following OT assessment needed appropriate equipment. This was refused by my boss as "cost outweighed benefit". The cost in question was £600. I ended up having to have three operations.

Although these were less frequently needed than flexible working, respondents still experienced problems from adjustments not being provided, even though this is a legal obligation on employers. Respondents indicated that this was a common problem and contributes to both having to leave a job, and being unable to take up a new one. Over 50% of respondents said that they experienced a lot of difficulty with getting work due to employers being inflexible about how work is carried out (58%) or not making a reasonable adjustment (65%). Consequently, there is a need for the government to consider how it can encourage, support and/or require employers to make adequate provision for people with chronic illness.

In the free-text responses, respondents wanted to see more encouragement for employers to take on disabled and chronically ill workers, including subsidising the costs



of the necessary adjustments or imposing quotas with fines if these are not met. It was felt that there should be more encouragement of flexible working and a greater willingness by employers to offer more reasonable adjustments and not just “start and end with a wheelchair ramp at the front door”. Claimants cannot be expected to find and keep work when employers are unwilling to take on or unable to afford the potential risk, and are not required to take an active part in retaining employees with chronic illness.

Key Points:

10. Employers may be reluctant to employ people with chronic illness due to founded or unfounded concerns of associated costs. Employers may need practical advice, support and/or financial assistance to make it viable for them to take on an employee where the any associated costs are uncertain.

11. There is a mismatch between what employers mean and can manage when they refer to flexible working, and what people with chronic illness mean and need when they refer to flexible working.

12. There is a difference between an individual being ‘capable’ of work (which could include working for small units of time at irregular intervals, spread out over a longer period), and an individual being employable or being able to find or sustain work.

2.5 Claimant Advocates

Respondents often indicated that the previous system, Incapacity Benefit, was better than ESA. This was for two reasons: one, that there were no conditionality or sanctions; and two, that the Disability Employment Advisers were in general more skilled than those currently working for the Jobcentre Plus or Work Programme providers. It was considered that old-style Disability Employment Advisors were more helpful, with a greater knowledge of the impact of disability as well as the types of opportunities potentially available in terms of re-training and supportive local employers.

Currently, the support offered to ESA claimants in WRAG is inadequate (Hale, 2014; Low, et al., 2015; Work and Pensions Committee, 2014; Welfare Conditionality, 2016) and is decreasing, as the number of disability employment advisers is being reduced (Low, et al., 2015). A report by cross-bench peers concluded that “the majority of employment support provided to people in the ESA WRAG is, at best, inappropriately targeted and, at worst, harmful” (ibid.).

> In the old days the DEAs were a real help. One got me into a retraining course, with a training allowance, and I got another job in a new field as a result.

Only a minority of respondents wanted the kind of support most offered by Work Programme providers, such as support for CV writing and interview (22%), workplace (20%) and motivational (19%) skills, and volunteering opportunities (20%). Instead, respondents want retraining (34%), access to a specialist employment advisor (36%), and the opportunity for a phased return to work (37%) – options not routinely provided. Additionally, claimants wanted improved access to healthcare (34-41%), supportive employers (59%) and the removal of sanctions and conditionality (67%).

> People should be given genuine help into (or back into) work, not cut-price, one-size-fits-all bullying; few will choose not to work if they genuinely can, and if they don't they may well have excellent reasons that don't fit the DWP's checklist.

> I want to return to my profession - teaching - but am being told to apply for low-skilled low-paid full-time jobs that are not suitable for my abilities and disability. I am on the Work Programme after being found Fit For Work by ATOS. I experience bullying and threats from the advisers. I am being forced into Workfare and not being given enough time to find a school to work in. I am not being supported in my chosen career path.

> Back to work support needs to be flexible for what people actually need. Many of the courses that currently happen are poor and shoddy and a waste of time for everyone. The CVs which result from courses are often unusable but the applicant has rock and hard place choice of use bad CV and not get work or use another CV which is better and risk jobcentre sanction for disobedience.

There was a strong sense from the free-text responses that support for moving back to work needed to be improved. Respondents wanted to see better Disability Employment Advisors with support tailored to the needs of the individual and funding or other assistance for retraining offered. However, respondents did not want a ‘requirement to engage’ or compulsion to seek work, preferring an opt-in for support if desired. This could include using financial bonuses to reward any engagement, and not applying sanctions for failure to engage.

> As a graduate I found the jobcentre incredibly patronising as they didn't understand what my degree was and kept insisting I should apply for jobs which I was not qualified for because one of the common words in the job description matched a word in my degree title.... advisers seem to have minimal training, be low paid, poorly clued up and often are private sector scams. My disability employment adviser at the JCP knew nothing about impairments or strategies for managing impairment in the workplace. He didn't know about specialist disability support organisations or internship schemes. I found those by myself.

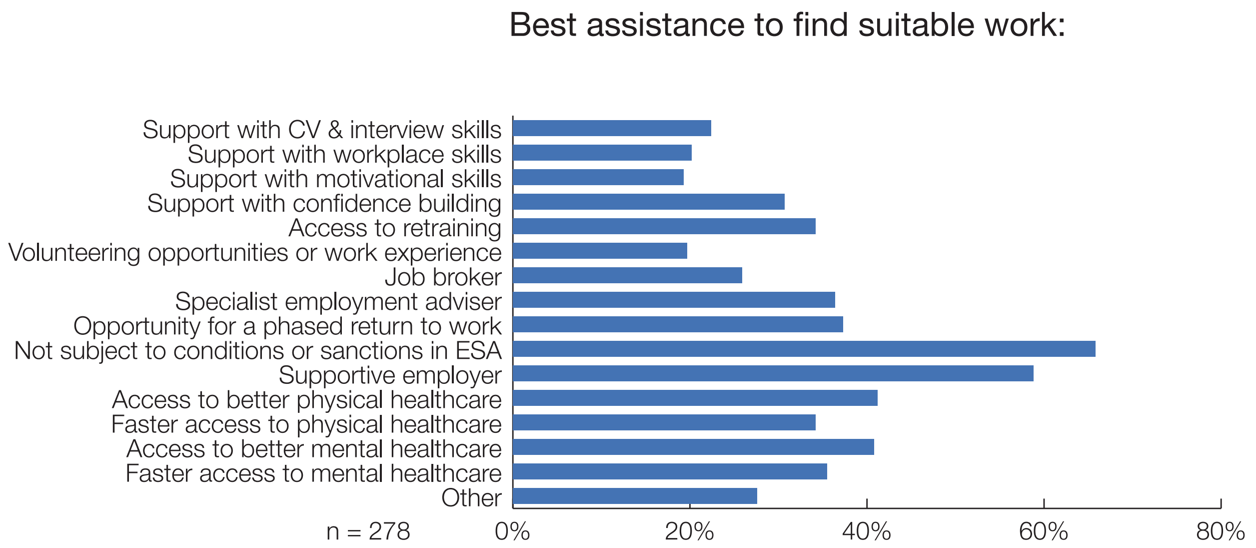
Caseworkers should have extensive knowledge of the available benefits, services and programmes (Nevile and Lohmann, 2011; Meershoek, 2012; OECD, 2003); the UK's DEAs used to be a good example (OECD, 2003). Caseworkers should have flexibility in how often they meet with claimants; those needing intensive support need more frequent meetings, whilst those doing well can manage with fewer meetings, and those with progressive conditions are unlikely to benefit as their support needs increase over time, making work increasingly less feasible. Caseworkers need small caseloads, in order to provide good support to their recipients (Nevile and Lohmann, 2011); providing inadequate support is a false economy, resulting only in the expenditure of money with no result.

Small work trials for minimal weekly hours can be beneficial, to explore the work an individual can do and what support is needed (Nevile and Lohmann, 2011; Meershoek, 2012; OECD, 2003). Support is also needed in work, to assist with changes in workplace, health and disability, job role or employer (Nevile and Lohmann, 2011). Individuals could also benefit from being allowed to try work, including through phased returns and voluntary positions, without losing their benefit or risking a re-assessment. The government may wish to recognise volunteering, community work and caring responsibilities as an adequate and appropriate return for the receipt of benefit, and therefore promote rather than discourage these forms of participation in society.

> Help finding appropriate jobs, and with retraining would be great. Appropriate (which is currently sub-standard and pointless) advice about work from home. Flexible working hours, home-work link.

> The people giving support should be adequately trained and there should be no incentives to them to stop people getting benefits.

> Support by specially trained staff with great understanding of what work may be suitable, what support is available, what training is available and which employers are willing to work with different medical conditions.



Key Points:

13. Employment advisers for people with chronic illness need to be highly trained and experienced, with extensive knowledge of the local job market, the impact of chronic illness on the ability to work, and the support available to people with chronic illness and disability.

14. Individuals should continue to receive benefit whilst undertaking training or voluntary work, or during work trials, to ensure financial stability and security.

Chapter 3: Assessment Criteria and Support

Many people with chronic illness have severe difficulty with work because of the diffuse nature of their condition and the way in which symptoms often affect, and are affected by, all activity. For example, someone whose illness causes them to be chronically fatigued will struggle with most activities because of the fatigue, and will be fatigued by most activities. I.e., people with chronic illness tend to struggle with all activities to some extent, rather than struggling severely with only a small number of activities (as the WCA is biased towards).

The consequence is that the WCA cannot assess people with chronic illness. Indeed the WCA Handbook makes it clear that some of the most debilitating parts of chronic illness – in particular the cognitive fatigue and its impact on intellectual function – are not covered by the descriptors. What is needed instead is an assessment that can consider the entirety of the individual's health, its impact on his or her life, and crucially the impact of work on both health and the other areas of the individual's life. Such a holistic assessment requires that areas external to health are also considered in the assessment, in order to understand both how these areas impact health and remaining capacity for work, and the consequences of work on the ability to carry out activities in other essential areas of life. A points-based, prescriptive assessment process is unsuitable for this kind of situation.

The starting point for an holistic assessment could be to ask individuals what work they could do, and what support they would need in order to be able to do it (Low, et al., 2015). This would tie in the issues raised above by the respondents to our survey. A number of countries already do this in their sickness benefit system, for example in the Scandinavian countries (Försäkringskassan, 2010; Spartacus Network, 2014). An assessment of fitness for work could then be based upon the assessor being able to find three or more jobs that the individual could perform without support (as in Denmark (AMS, 2010)). This would provide a more realistic and transparent result, and its use in other countries shows that it is feasible.

Any work identified by the assessor should be in the open labour market, and specifically exclude self-employment, zero-hour contracts, commission-based pay or other such piecemeal and insecure work. It may additionally be beneficial to include consideration of the individual's labour market competitiveness, as recommended by the OECD (2010), in order to take the employer's abilities into account.

Support for work, as identified by our respondents, falls into four categories: support outside of the workplace; support to prepare for work; support in the workplace for the employee; and support in the workplace for the employer. Support to prepare for work is discussed in the next chapter. In all cases, support should be provided up-front before asking individuals to prepare for, look for or take up work. In particular, it is useful for employers to know that any necessary in-work support, aids or adaptations are available immediately upon employment, in order that they can be confident that the applicant will be able to carry out the job being applied for.

The OECD notes that for some people, supporting them into work could "require more resources than a society can or wants to devote". For our respondents, this is particularly pertinent where the energy and health expended on work would mean that they move from being able to take care of themselves, their house and their dependents to needing support in some or all of these areas. It may be advisable to focus on providing adequate outside-of-work support for all disabled people, and good in-work support for those closest to the labour market, before looking at how to assist those further from the labour market into work.

Key Points:

15. A decision of fit for work should be based upon the ability to identify jobs that that individual could perform.

16. If an individual needs particular forms of support to be able to work, that individual is considered unfit for work unless and until that support is provided.

3.1 Support Outside of the Workplace

The responses to this survey indicate that in order to be able to work, support is necessary outside of the work-place. These needs include healthcare, personal assistance (partially covered by social care), assistance in maintaining and running a home (partially covered by Personal Independence Payment), and the provision of alternative support for dependents. These are areas that have experienced cuts or freezes in funding since 2010, and some (such as certain household tasks) have never been supported at all.

Because individuals with chronic illness face barriers across a range of activities, not merely work, it is necessary to address all these barriers if work is to be achievable. In particular, it is vital that individuals receive good, prompt healthcare; receive the support they need for personal care and household maintenance; and have an income that is stable and sufficient for social participation as well as for meeting essential needs. This should be made available to all individuals with chronic illness before focusing on getting such people into work. Such pre-work support includes, but is not limited to:

1. Adequate healthcare. People with chronic illness report, in both this and other reports (e.g. (Sainsbury and Davidson, 2006), that they struggle to receive timely and appropriate healthcare. If not treated early enough, short-term illnesses can become long-term, and long-term illnesses can develop complications or become intractable to treatment (Wang, et al., 2004; Fritz, et al., 2012). The cost of treatment increases, the person suffers a reduced quality of life, and the country loses workers to illness. The government may wish to consider increasing funding to the NHS in order to treat illnesses promptly and reduce the incidence of preventable disease.

2. Adequate support at home. People with chronic illness often experience difficulty in most areas of life due to pain and fatigue. Undertaking one activity can prevent the ability to undertake another, totally different, activity. Consequently, these people need support in all areas, and especially so if they are to devote some of their energy and capacity for activity to paid work.

   Currently, there is no provision from the government for tasks such as cleaning and maintaining a safe home environment, shopping, laundry and additional costs arising from needs such as higher utility bills or specialist foods. It is vital that this support be provided. The government may wish to reconsider what areas are covered by social care and what is covered by disability benefits, in order to ensure that some areas are not covered twice whilst others are not covered at all. The government may need to increase funding in order to provide the necessary personal assistance, home care and extra costs arising from chronic illness and disability.

3. Assistance with caring responsibilities. People with chronic illness may also have childcare and other caring responsibilities, and fulfilling these duties can impact on the remaining capacity for work (Dekkers-Sanchez, et al., 2010). It is vital that adequate support is provided to both the carer and the caree(s). In particular, assistance for child care when the parent is disabled is not well covered by either child or adult social work.

4. Use the ‘first do no harm’ principle, particularly for conditions that can be made worse by over-activity or stress. The principles of pacing should be used, in which the starting point for activity is half of what the person can manage without making her symptoms worse. It is important that claimants are safeguarded against the risk of being asked to take part in activity that is beyond them. This allows a more sustained and less risky movement towards, and return to, work.

3.2 Support to Prepare for Work

Once the pre-work support has been put in place, it becomes feasible to assist the individual to prepare for work. Our respondents indicated that, contrary to the support most commonly provided by the Work Programme and JobCentre Plus, support for CV writing, interview skills and other basic employment habits is not often needed. Instead, claimants want re-training (to compensate for no longer being able to use previous skills) and phased returns to work (in order to allow a gradual increase or change in activity). Our respondents also wanted improved healthcare (discussed above), supportive employers (discussed below) and specialist employment advisers. This is markedly different from the basic service currently provided to people with chronic illness. People with chronic illness do not suffer from a motivational or work ethic problem; they suffer from ill-health.

Providing such support might involve combining and expanding current provision. At the moment, support for people with an employment contract includes the Fit For Work scheme (occupational health assessments) and Access to Work (funding for necessary support in the workplace). However, the Fit for Work scheme is voluntary and its recommendations are unenforceable. We recommend that participation in the Fit for Work scheme becomes compulsory for all employers, and that the recommendations made by the occupational health assessor have to be put in place. Access to Work may also need to be overhauled, including being available up-front before an individual applies for a job, so that both the individual and the prospective employer can be confident of the immediate provision of any necessary support.

Even with appropriate support, people with chronic illness and disability may find they are not offered work because employers have concerns regarding productivity and the costs of managing a person with illness or disability. The support worker must be able to liaise with employers to alleviate unfounded fears, and to assure the employer of the support that the claimant will bring with them. The government may need to be responsible for providing protection for the employer against relevant costs, such as paid disability leave during flare-ups or for medical appointments. Without this support, the claimant is not competing for jobs on an equal footing with healthy and able-bodied job applicants, and consequently it is unreasonable to expect these claimants to receive job offers without support from the claimant advocate and the government.

For all claimants the support worker role includes instating out-of-work support such as access to healthcare and assistance at home; and support to prepare for work such as re-training or up-skilling.

3.3 Support in the Workplace

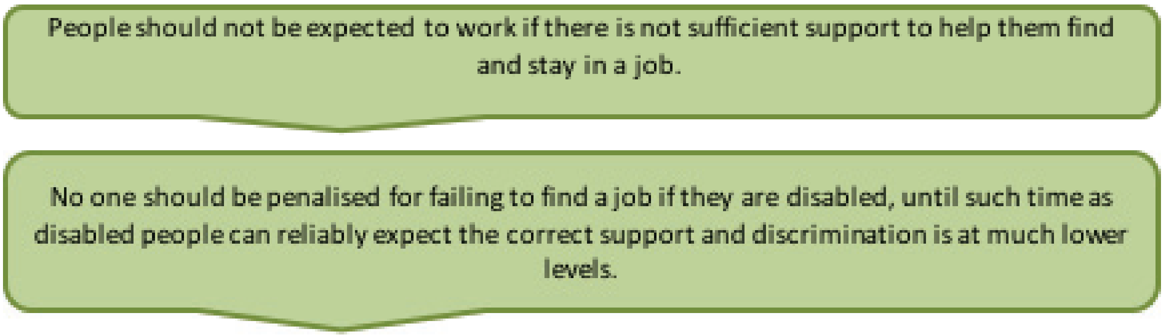
Employers may be reluctant to employ people with chronic illness due to founded or unfounded concerns of associated costs. Employers may need practical advice, support and/or financial assistance to make it viable for employers to take on an employee where the employer is uncertain regarding financial risk.

In order to support people with chronic illness to be able to work, the government may need to provide a range of support to both claimants and prospective or current employers. Claimants need a range of adaptations, and these often present costs to the employer. Some are one-off costs such as adapted work environments, but others are ongoing such as managing flexible working and time off.

These costs include:

1. Managing work-flow when an individual may need time off to manage flare-ups, attend appointments, take rest breaks or deal with emergencies.
2. Paying for disability leave when an employee needs time off due to a flare-up. Disability leave should be paid from the first day of leave, and not have the delay that occurs for sick leave.
3. Adapting the workplace to make it and the workstation physically accessible.
4. Providing additional technology to assist the employee in their work.
5. Providing extra time to learn new tasks.
6. Paying for a support worker, for either all or some of the time.
7. The possibility of reduced work-flow compared to healthy, able-bodied adults as a result of an illness or disability.

These costs are not insignificant and present a barrier to employers wishing to employ a person with chronic illness or disability. Unless the government compensates employers for these costs, or imposes and enforces a quota system, people with chronic illness will be significantly less likely to be offered work even when they could work if given the appropriate support. Employers may also need assistance to know what is appropriate and necessary support for an employee with a chronic illness in a specific job role.



People should not be expected to work if there is not sufficient support to help them find and stay in a job.

No one should be penalised for failing to find a job if they are disabled, until such time as disabled people can reliably expect the correct support and discrimination is at much lower levels.

Conclusion

This report confirms the findings of many other researchers (Hale, 2014; Spartacus Network, 2014; Work and Pensions Committee, 2014) that the WCA is not fit for purpose. In the course of our research we consulted a number of DPOs and interested parties including politicians across the political spectrum. The vast majority of these agreed that it is time for a new system.

In our next report we will draw up ideas about what this system might look like for further consultation. We believe it needs to be based on the following principles:

1. Individuals contribute to society in a number of ways other than paid work, and the value of these contributions should be recognised.
2. A range of areas not well captured by the WCA are key to the understanding and assessment of capacity for work. These include mental health, varying or unpredictable capacity for work, and the accumulation of incapacity from multiple origins.
3. The social security system needs to protect those whose health and quality of life is at risk of being damaged by requirements to engage in work or work-related activity.
4. The decision of capacity for work should include labour market competitiveness.
5. The assessment should consider the overall capacity for work, including the need to work at a slower pace or have breaks from work, rather than focusing on isolated activities.
6. Capacity for work is impacted by the provision of support in areas of life outside of the individual workplace. These can include health care, personal assistance, home help, caring responsibilities, commuting and regulation of the labour market to promote more and better quality jobs.
7. People with chronic illness need a wide range of support if they are to be able to work
8. People with chronic illness may benefit from re-training, particularly where re-training may allow the individual to use remaining health capacity better or compensate for loss of capacity in a previously trained area.
9. The assessment should give direct consideration to the skills that the individual has and whether or not these can be used given the claimant’s health condition.
10. Employers may be reluctant to employ people with chronic illness due to founded or unfounded concerns of associated costs. Employers may need practical advice, support and/or financial assistance to make it viable for them to take on an employee where any associated costs are uncertain.
11. There is a mismatch between what employers mean and can manage when they refer to flexible working, and what people with chronic illness mean and need when they refer to flexible working.
12. There is a difference between an individual being ‘capable’ of work (which could

include working for small units of time at irregular intervals, spread out over a longer period), and an individual being employable or being able to find or sustain work.

13. Employment advisers for people with chronic illness need to be highly trained and experienced, with extensive knowledge of the local job market, the impact of chronic illness on the ability to work, and the support available to people with chronic illness and disability.
14. Individuals should continue to receive benefit whilst undertaking training or voluntary work, or during work trials, to ensure financial stability and security.
15. A decision of fit for work should be based upon the ability to identify jobs that the individual could perform.
16. If an individual needs particular forms of support to be able to work, that individual is considered unfit for work unless and until that support is provided.

This report shows that the system as it stands means that people with chronic illness are being abandoned: they are abandoned in work, refused the adaptions they need; they are abandoned on JSA, assumed to face no more barriers than any other jobseeker; they are abandoned on ESA WRAG, forced to take part in ineffective activity yet rarely, if ever, offered the level of support they would need to be able to work. The government claimed that the Incapacity Benefit system abandoned disabled people to a life on benefits. Yet people with chronic illness feel far more abandoned on ESA. Under IB they were given the freedom to live and manage their lives; on ESA they are mandated to activites beyond their capabilities without the extensive support necessary to undertake these activities.

The necessary support is expensive and wide-ranging: from health, social and child care; through local jobs and improved public transport; to flexible hours, paid disability leave and compensation for employers. Without such support, any attempts to get people with chronic illness into work are simply doomed to fail. Not only that, but it is a waste of resources to put money into a scheme that cannot work – including where, ironically, it is the lack of sufficient funding that means the scheme won't work – and a waste of people's health, energy and capacity for social inclusion.

The government can provide the support needed for those with chronic illness to work, and then ask such people to undertake that work, or they can reduce expenditure and allow those with chronic illness to live lives that contribute in other ways, without conditions. But the government cannot have it both ways. It cannot refuse to pay the cost of employment support and simultaneously insist that individuals with chronic illness 'prepare for' work that they will never find.

The principles we propose allow the government to make that choice. By basing the decision upon what support is needed for an individual to work, we ensure that the decision on capacity for work is tied in to both what support an employer can provide, and what the government is providing. We will end the farcical situation where individuals are told by the DWP's mechanistic system that they are fit for work, when the assessor and employment support worker know that the individual is demonstrably unfit for work. And we will ensure that no-one is asked to work before the government has made it possible for them to do so.

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Appendix

This Appendix contains more detail on the results from the survey, and the tables of results for all the questions. This includes results from questions on the assessment design and process, which will be presented in our next report.

Background data

The respondents to the survey are predominantly female (70%) and over forty (73%) with 40% in the 51-60 age bracket alone.

Over half of the respondents are in the Support Group of ESA (52%), whilst one quarter are not on ESA at all (24%). 14.5% are in the WRAG. Of the rest, two were found fit for work and did not appeal (0.7%) whilst eight are appealing a FFW decision (2.8%). 10 were waiting for a decision (3.5%), and seven were on Incapacity Benefit or Income Support (2.4%).

Over half have not worked for at least five years (55%), whilst a fifth left work between one and five years ago (21%). Some people (6.6%) have never worked; this group was on average younger than the rest of the respondents, with an average age of 31. Some of the respondents were in full-time work at the time of the survey (5% working over 35 hours per week; 3.1% working 26-35 hours per week) whilst others did a small amount of work (4.3% worked up to 15 hours per week) or worked part-time hours (2.7% worked 16-25 hours/week). Whilst a large proportion were not in any paid work, even part-time (85%), 55% of respondents were engaged in some form of activity whether paid work (55%), studying or voluntary work (40%) or caring duties (30%). For most people, this was less than fifteen hours per week.

A number of respondents report that they experience or have experienced a lot of difficulties in areas relating to discrimination (29%), education (25%), housing (35%) and public transport (41%). The majority of respondents experience or have experienced at least some difficulty in each of these areas, particularly in relation to public transport (84%). Hate crime is less common, with 12% reporting a lot of hate crime.

Healthcare has presented significant difficulties to our survey respondents: less than 13% report that they can access appropriate or timely healthcare, whilst around half report a lot of difficulties with healthcare.

Health Problems

Physical health problems (83%) were more common than mental health problems (60%). There was overlap between the two, with 71% of people with mental health problems also having physical health problems, and 51% of those with physical health problems also experiencing mental health problems (i.e., 42.5% had both). A small number also reported problems such as learning disabilities or an autism spectrum disorder (8.5%; all with a mental health and/or physical health problem as well)

More than half experience fairly severe or severe difficulties arising from pain (60%), fatigue (76.5%; 56% with severe fatigue), poor concentration (67%), anxiety (52%), difficulty being in a workplace (57%), and mobility issues (58.4%). Between 40 and 50% report difficulties with using their hands and arms (41%), social interaction

(42%), completing tasks (48%) and coping with change (46%).

Over half also report that side-effects from medicine cause them fatigue (55.5%), whilst more than two in five report that side-effects lead to pain (43%) and difficulties with concentration (43%), mobility (42%) and being in a workplace (40.5%).

Over half say that variation in symptoms (52%) and severity (56%) cause severe difficulties for work. The risk of making health worse (59%) and the need for time off unpredictably (68%) also cause severe difficulties for the majority of people. Including the figures for 'fairly severe' difficulties brought these figures to 80% or more.

Over half experience fairly severe or severe difficulty from the need to work at a slower pace (57%), time off for medical appointments (53%) and the need for either rest breaks during work (61%) or unexpected breaks such as an epileptic fit (66%).

Respondents particularly reported struggling with work that requires being on their feet or walking (49%), or is physically (56.5%) or emotionally challenging (48%).

Finding and Keeping work

We asked respondents why, if they had to leave work due to a health condition, this was the case (q15). The responses were analysed using content analysis to discover what themes and topics were mentioned by respondents. The responses were categorised into one of six themes: employer-related issues; work-related issues; insufficient support; physical symptoms, mental symptoms and other. Because this is a free text response; topics are not mentioned at the same frequency in these as they are selected in tick-box questions.

The most common topic was that the respondent could not do that specific job role (25.3%), e.g. they were no longer able to work as a nurse. The next two were pain (20.8%) and fatigue (18.2%), which were also chosen by over 50% of respondents as causing severe or fairly severe problems in terms of ability to work (see above). Mental and cognitive issues also featured relatively frequently in the comments, with stress or a nervous breakdown (14.9%), depression (14.3%) and cognitive problems (13.6%) being the most common. This matches the tick-box options, where these issues were chosen over 50% of the time as causing severe or fairly severe problems.

Respondents raised issues with employers not offering adaptations or adjustments, even where these would have been possible (13.6%; 65% in q21). Other topics commonly raised were the need for a lot of time off work (16.9%) or that the respondent was unable to do any job at all (13.6%; 46% chose this option in q17).

Question 16 asked respondents what it was about their health condition that made work difficult. This elicited similar topics to q15, although there was less emphasis on an employer's actions. As in q15 and q11, fatigue (43.5%), pain (33.5%), cognitive problems (30.9%) and anxiety (23%) came up frequently. Less frequently mentioned, but still relatively common, were mental health issues stemming from depression (15.2%) and social or agoraphobia (13.1%), and physical health difficulties with mobility (17.8%) and sitting or standing even for short periods (12%).

Another common issue was that work or activity would make the respondent's health worse (14.7%); this was also seen in q13 where 59% said this caused severe difficulty for work; and q17 where 46% said they could not work at all. Finally, respondents also cited employers' attitudes and the lack of support or adjustments as barriers that make work difficult (12%). Other issues raised by fewer respondents can be seen in the table for q16.

In response to q17 (whether they could work full-, part-time or not at all), 44% of respondents considered that they could manage part-time work if they had the right job and support, and a further 10% thought that they could manage full-time work. 46% said that, even if support were available, they would still be unable to work even part-time.

The options most often chosen for q18 (what stops one working, even with support) were transport and commuting (62%), not being able to find a suitable job to apply for (51%) and health problems meaning one can't continue with a previous line of work (63%). The least common difficulties were with finding jobs at lower hours (22.3%), being turned down by employers (21%), lack of motivation (21%) and a lack of recent job-applicable skills (21%).

In order to be able to work (q19), there is a need for flexible hours (71%), work from home (65%), paid disability leave (52%) and relaxed disciplinary procedures (44%). Even more say they need access to better physical (77%) and mental (78%) healthcare. Many also say that they would need a supportive employer (71.5%) and colleagues (64%).

In terms of support needed for finding work (q20), respondents were strongly against conditionality and sanctions (67%). There is a need for supportive employers (59%), and access to better mental and physical healthcare (both at 41%). Least popular were support for developing CV writing or interview (22%), workplace (20%) and motivational (19%) skills, and access to volunteering opportunities (20%).

In response to question 21, respondents were concerned about the problems they experienced due to employers' attitudes and behaviour, and due to problems with healthcare. Over 50% of respondents said that they experienced a lot of difficulty with getting work due to employers being inflexible about how work is carried out (58%), a perception by employers that people with long-term illness are less productive (58%), employers' fear of employing people with long-term illness (LTI) (63%), an expectation by employers that it is too costly to employ people with LTI (66%), and discrimination by employers (59%). Over 50% also felt that they experienced a lot or quite a lot of difficulty due to employers not making reasonable adjustment (65%) or combating bullying and harassment from colleagues (64%). Similarly, many experienced a lot or quite a lot of difficulty due to delays in getting necessary healthcare (59%) or not being able to get healthcare (54.5%).

In q22, respondents were asked to say in their own words what support they need to work. 32% said that they could not work at all, even though this did not itself answer the question. The three largest topics relating to specified support were the need for supportive and understanding employers (22.5%), for flexible working (21.7%), and for the ability to work from home (21%). This corroborates the responses to q19 and 21.

13% said that they needed better and/or faster healthcare; this could be in reference to physical healthcare, mental healthcare, both or unspecified. The next largest group of topics referred largely to workplace modifications and support: contracts based on commissioned outcomes or without deadlines (10.9%); limited or part-time hours (9.4%); ergonomic workstations such as a suitable desk, chair, keyboard and mouse (9.4%); and support from another adult in the form of a PA, carer or support worker (9.4%).

Redesigning ESA

Over 50% consider that it is important or very important to consider an individual's skills and experience (65%), whether these can be used given the individual's health conditions (78%), the need for help with home responsibilities (66%) and the need for help with caring responsibilities (62%) when assessing an individual's capacity for work. Over 50% say it would be very important to consider the need for personal care (58%), the availability of jobs locally (61%) and the ability to commute to work (54%).

In terms of issues not well covered by the WCA, over 80% said that it was very important that consideration be given to pain (84%), fatigue (85%), concentration (83%) and the need for unexpected breaks whilst at work (82%) or time away from work (81%). Over 60% also wanted the ability to work under pressure (65% and to deadlines (64%) to be considered, as well as the impact of anticipated time off work, such as for rest breaks (62%) or medical appointments (69%). 79.5% considered that the impact of psychological distress was also very important to an assessment of capacity for work.

A large proportion of people want either their own GP (89% agree or strongly agree) or a medical specialist in their condition (85% agree or strongly agree) to carry out the assessment. The current situation, where generalists or those specialised in other conditions carry out assessments, was very unpopular with 84% disagreeing that this was suitable.

There was high support for professional evidence to be included before an assessment with 78% saying one's GP should always give evidence, and 69% wanting the professional most involved in their care to always give evidence. Other forms of evidence could be included if either the assessor or the claimant thought it appropriate, but it was not largely felt that these should be submitted in every case. It was strongly felt that medical evidence should be collected and read before a face-to-face assessment is carried out (92%).

There was strong support for being able to comment on the assessor's report before a decision is made, with 86% saying this should definitely happen. A majority (55%) also felt that the assessment should have to identify possible jobs before finding someone fit for work, rising to 78% when those saying this might (rather than definitely would) be helpful are included.

The majority of respondents felt that it might or definitely would be helpful if there could be several meetings with an assessor before a decision is made (75%), the assessor was also the decision maker (64.5%), and the assessment explored ways to assist a move into work (66%). There was an even split between those who felt decisions should always be on paper (45%) and those who accepted a face-to-face element (44%).

In terms of a requirement to look for work, there was some approval of having a specific ESA group for certain groups of people including those who could work full-time with the right support but are limited in the range of jobs they could do (56%), those who could work part-time (48%), and those who could work if they had re-training (46%). However, for each of these, over 20% thought people who fit these groups should not have any requirement to engage. The majority considered that those with a self-limiting (55%), progressive (90%) or terminal illness (93%) should not have any requirement to engage with moving towards work. No-one thought people in the latter two groups should either be on JSA or in a general ESA group with requirement to engage (equivalent to WRAG).

The last question asked respondents for any further comments, and invited them to describe what a sickness benefit would look like if they could design it from scratch. Respondents collectively addressed a large range of topics and themes in their answers to this question.

Respondents identified several areas of concern with the current system. There was a strong feeling among some respondents that claimants were treated as being irresponsible or less than human during the assessment process (10.7%). Additionally, respondents said that the current system was overly suspicious, assuming a high rate of fraud (7.4%) and setting out to deliberately cut the number of successful claims (6%).

Some respondents cited the previous system as being better (7.4%), with a particular emphasis on the old-style Disability Employment Advisors being more helpful, having a greater knowledge of the impact of disability as well as the types of opportunities potentially available in terms of re-training and supportive local employers.

There was a strong emphasis on the need for more knowledgeable assessors. Some felt the claimant’s own GP or primary consultant should be the one undertaking the assessment and making the decision (14.1%) while others said the assessment should be done by a specialist with knowledge of the claimant’s condition (18.8%). A smaller number thought that any doctor or professional within the NHS would be suitable assessors (8.1%). There was concern that the decision should be made independently, i.e. not by the DWP or by anyone working under a DWP contract that embodied targets to reduce claimant numbers (10.7%). Some respondents said that their GP or primary consultant should be involved and consulted before a decision is made (6%).

There was a call for greater weight to be placed on the medical evidence submitted (12.1%) and for evidence to be collected from all the consultants involved in the claimant’s care and considered before the assessment takes place (14.1%). Respondents said that the DWP should not be permitted to dismiss evidence submitted to them and should have to justify their decision (8.1%). In particular, the DWP should not find someone fit for work if their GP had given them a sick note or their primary consultant felt they were unable to work.

It was felt that certain conditions should not require an assessment or should lead to a permanent award with no reassessments. Permanent awards were felt to be most appropriate for progressive or terminal conditions, permanent disabilities and those with profound and multiple learning difficulties (14.8%).

Respondents wanted to either retain the current distinction between those (ostensibly) permanently incapable of work and those (ostensibly) expected to recover (6.7%) or wanted more categories, to cover the difference between short-term sick, permanent disabilities and those with a long-term or chronic illness (6.7%).

A number of conditions were considered to be given insufficient weighting in the current system and it was felt that a better awareness, understanding and support of these conditions is needed. The main conditions identified were mental health (20), chronic illness (17), pain and fatigue (11) and fluctuating conditions (9). Respondents wanted a more holistic assessment (23) and felt that the current tick box approach and tasks chosen as descriptors were inappropriate (12).

Respondents felt that whether the claimant was likely to get a job in the current job market should also be considered in the assessment (13). This included whether the necessary adaptations were likely to be provided and how a potential employer would view the claimant.

A number of respondents said that interviews should be avoided wherever possible (6%), with decisions being based on the medical evidence submitted.

There was a broad feeling that the benefit paid should be higher (6.7%), reflecting the additional difficulties that disabled people experience in finding and retaining employment, and recognising that Job Seeker’s Allowance is deliberately insufficient for anything other than a very short term income. Some respondents suggested a ‘Citizen’s Income’ (6%).

It was felt that the current system was not sufficiently enabling of an attempt to try work again. Respondents said that claimants should not suffer financially should they try to work again but be unable to sustain the role. It was felt that benefits should continue while work was trialled or that the claimant should be able to return to the benefit without reassessment (14.1%). Respondents felt that benefits should still be awarded when a person was volunteering, working part-time or self-employed (10.7%).

There was a strong sense that support for moving back to work needed to be improved. Respondents wanted to see better Disability Employment Advisors (19.5%) with support tailored to the needs of the individual (10.7%) and funding or other assistance for retraining offered (9.4%). However, respondents did not want a ‘requirement to engage’ or compulsion to seek work (9.4%), preferring an opt-in for support if desired (8.7%). Respondents said that it was important for health needs to be met before expecting the claimant to engage in work-related activities (6%).

Some respondents said that sanctions were inappropriate and should never be used (31.5%) while others said that incentives, for example a bonus, would be beneficial (8.1%).

More encouragement for employers to take on disabled and chronically sick workers is suggested (8.7%), including subsidising the costs of the necessary adjustments or imposing quotas with fines if they are not met. It was felt that there should be more encouragement of flexible working and a greater willingness by employers to offer more reasonable adjustments and not just ‘start and end with a wheelchair ramp at the front door’ (8.1%).

Universal Credit was either rejected or it was felt that sickness and disability benefits should be separate (6%).

1. What age bracket are you in?

Age bracket	# respondents	% respondents
16-20	5	1.70%
21-25	10	3.40%
26-30	18	6.20%
31-35	29	10%
36-40	17	5.90%
41-45	34	11.70%
46-50	37	12.80%
51-55	66	22.80%
56-60	49	16.90%
61-65	24	8.30%
65+	1	0.30%

2. What is your gender identity?

Gender	# respondents	% respondents
Male	82	28.30%
Female	202	69.70%
Prefer not to say	3	1%
Other	3	1%

3. Do you currently claim Employment and Support Allowance (ESA)?

	#	%
I am not currently on ESA and am not waiting for an assessment, decision or appeal	70	24.20%
I was found fit for work in the past year, and I am not putting in an appeal	2	0.70%
I was found fit for work in the past year, and I have put in an appeal	8	2.80%
I have put in a claim for ESA and am waiting for an assessment	10	3.50%
I am currently in the Work-Related Activity Group of ESA	42	14.50%
I am currently in the Support Group of ESA	150	51.90%
I am currently on Incapacity Benefit or Income Support	7	2.40%

4. Which of the following have you experienced difficulty with, either now or in the past?

	Never	A little, in the past	A lot, in the past	A little, and it is ongoing	A lot, and it is ongoing
Accessing education	115	62	35	18	33
	43.70%	23.60%	13.30%	6.80%	12.50%

Housing	96	68	57	14	39
	35%	24.80%	20.80%	5.10%	14.20%
Public transport	45	52	15	65	98
	16.40%	18.90%	5.50%	23.60%	35.60%
Hate crime	144	62	19	38	14
	52%	22.40%	6.90%	13.70%	5.10%
Discrimination	62	55	30	82	52
	22.10%	19.60%	10.70%	29.20%	18.50%
Appropriate healthcare	32	46	54	61	92
	11.20%	16.10%	18.90%	21.40%	32.30%
Timely healthcare	36	46	55	64	84
	12.60%	16.10%	19.30%	22.50%	29.50%

5. When did you last work?

Time since last in work	#	%
in work	36	12.40%
0-3 months ago	3	1%
3-6 months ago	1	0.30%
6-12 months ago	10	3.40%
1-2 years ago	14	4.80%
2-5 years ago	46	15.90%
5-10 years ago	69	23.80%
More than 10 years ago	92	31.70%
I have never worked	19	6.60%

6. If you are currently in work, how much paid work do you do a week, on average?

Hours in work/week	#	%
None	219	84.90%
1-5 hours	6	2.30%
6-10 hours	4	1.60%
11-15 hours	1	0.40%
16-20 hours	5	1.90%
21-25 hours	2	0.80%
26-30 hours	5	1.90%
31-35 hours	3	1.20%
36+ hours	13	5%

7. How much studying or voluntary work do you do a week, on average?

Hours volunteering or studying/week	#	%
None	170	59.40%
1-5 hours	65	22.70%
6-10 hours	21	7.30%
11-15 hours	15	5.20%
16-20 hours	8	2.80%
21-25 hours	4	1.40%
26-30 hours	2	0.70%
31-35 hours	0	0%
36+ hours	1	0.30%

8. How much caring work do you do a week, on average?

Hours spent caring/week	#	%
None	202	70.40%
1-5 hours	27	9.40%
6-10 hours	16	5.60%
11-15 hours	8	2.80%
16-20 hours	3	1%
21-25 hours	4	1.40%
26-30 hours	1	0.30%
31-35 hours	4	1.40%
36+ hours	22	7.70%

9. Which of the following tasks did your last job involve?

	Never	Occasionally	Sometimes	Most of the time	All the time
Managing people below you	77	42	46	37	55
	30%	16.30%	17.90%	14.40%	21.40%
Talking to or working with colleagues	6	11	33	80	133
	2.30%	4.20%	12.50%	30.40%	50.60%
Talking to clients, customers or service users	16	28	45	51	123
	6.10%	10.60%	17.10%	19.40%	46.80%
Cognitively challenging work	19	22	48	62	112
	7.20%	8.40%	18.30%	23.60%	42.60%
Physically challenging work	70	51	60	38	45
	26.50%	19.30%	22.70%	14.40%	17%

Emotionally challenging work	32	43	60	59	67
	12.30%	16.50%	23%	22.60%	25.70%
Being on your feet, or walking	34	51	83	38	59
	12.80%	19.20%	31.30%	14.30%	22.30%
Sitting at a desk or other workstation	19	42	62	92	47
	7.30%	16%	23.70%	35.10%	17.90%
Driving	142	39	55	11	17
	53.80%	14.80%	20.80%	4.20%	6.40%
Small movements	20	19	58	77	90
	7.60%	7.20%	22%	29.20%	34.10%
Larger movements	46	56	76	35	52
	17.40%	21.10%	28.70%	13.20%	19.60%

10. Are your difficulties with work related to mental health condition(s), physical health condition(s), or both?

	#	%
MH	45	16%
PH	110	39%
LD	0	0%
MH+PH	103	36.50%
MH+LD	4	1.40%
PH+LD	3	1.10%
MH+PH+LD	17	6%

(mental health, physical health and learning difficulties/other)

11. How much difficulty do you experience in the following areas, in terms of your ability to work, as a direct result of your health condition(s)? Issues caused by your medication or other health interventions are addressed in the next question.

	Not a problem or no impact on ability to work	Mild impact	Moderate impact	Fairly severe impact	Severe impact on ability to work
Pain	40	28	43	41	126
	14.40%	10.10%	15.50%	14.70%	45.30%
Fatigue	5	12	50	59	159
	1.80%	4.20%	17.50%	20.70%	55.80%
Anxiety	38	43	54	52	94
	13.50%	15.30%	19.20%	18.50%	33.50%

Concentration	12	31	52	78	111
	4.20%	10.90%	18.30%	27.50%	39.10%
Communication	46	56	70	68	41
	16.40%	19.90%	24.90%	24.20%	14.60%
Mobility	40	26	52	47	119
	14.10%	9.20%	18.30%	16.50%	41.90%
Hands and arms	83	33	51	54	60
	29.50%	11.70%	18.10%	19.20%	21.40%
Sight	174	49	33	15	11
	61.70%	17.40%	11.70%	5.30%	3.90%
Hearing	183	42	32	13	10
	65.40%	15%	11.40%	4.60%	3.60%
Continence	151	50	33	23	27
	53.20%	17.60%	11.60%	8.10%	9.50%
Consciousness	201	29	22	16	12
	71.80%	10.40%	7.90%	5.70%	4.30%
Social interaction	46	42	75	58	61
	16.30%	14.90%	26.60%	20.60%	21.60%
Being in a workplace	40	32	48	72	89
	14.20%	11.40%	17.10%	25.60%	31.70%
Coping with sensory information	85	41	62	55	38
	30.20%	14.60%	22.10%	19.60%	13.50%
Learning new tasks	73	51	75	52	30
	26%	18.10%	26.70%	18.50%	10.70%
Completing tasks	47	36	64	70	64
	16.70%	12.80%	22.80%	24.90%	22.80%
Following instructions	80	53	74	48	25
	28.60%	18.90%	26.40%	17.10%	8.90%
Coping with change	46	49	58	63	67
	16.30%	17.30%	20.50%	22.30%	23.70%
Keeping yourself safe	70	57	54	43	59
	24.70%	20.10%	19.10%	15.20%	20.80%

12. How much difficulty do you experience in the following areas, in terms of your ability to work, due to the effects of your medication, treatment, therapy or other health interventions?

	Not a problem or no impact on ability to work	Mild impact	Moderate impact	Fairly severe impact	Severe impact on ability to work
Pain	99	27	32	39	78
	36%	9.80%	11.60%	14.20%	28.40%
Fatigue	50	21	51	48	104
	18.20%	7.70%	18.60%	17.50%	38%
Anxiety	87	40	59	27	60
	31.90%	14.70%	21.60%	9.90%	22%
Concentration	62	41	55	48	70
	22.50%	14.90%	19.90%	17.40%	25.40%
Communication	109	46	50	34	33
	40.10%	16.90%	18.40%	12.50%	12.10%
Mobility	101	29	30	35	80
	36.70%	10.50%	10.90%	12.70%	29.10%
Hands and arms	131	38	30	31	43
	48%	13.90%	11%	11.40%	15.80%
Sight	184	48	18	13	9
	67.60%	17.60%	6.60%	4.80%	3.30%
Hearing	201	32	22	11	7
	73.60%	11.70%	8.10%	4%	2.60%
Continence	183	22	32	12	24
	67%	8.10%	11.70%	4.40%	8.80%
Consciousness	196	18	23	15	17
	72.90%	6.70%	8.60%	5.60%	6.30%
Social interaction	111	38	56	35	35
	40.40%	13.80%	20.40%	12.70%	12.70%
Being in a workplace	90	34	40	44	68
	32.60%	12.30%	14.50%	15.90%	24.60%
Coping with sensory information	130	33	43	36	31
	47.60%	12.10%	15.80%	13.20%	11.40%
Learning new tasks	102	54	41	46	32
	37.10%	19.60%	14.90%	16.70%	11.60%
Completing tasks	97	28	49	53	47
	35.40%	10.20%	17.90%	19.30%	17.20%

Coping with change	112	35	45	35	49
	40.60%	12.70%	16.30%	12.70%	17.80%
Keeping yourself safe	118	41	36	26	55
	42.80%	14.90%	13%	9.40%	19.90%

13. How much of an impact do the following factors have on your ability to work?

	Not a problem or no impact on ability to work	Mild impact	Moderate impact	Fairly severe impact	Severe impact on ability to work
The symptoms you experience vary	6	19	33	77	148
	2.12%	6.71%	11.66%	27.21%	52.30%
The severity of symptoms you experience varies	5	11	25	82	158
	1.78%	3.91%	8.90%	29.18%	56.23%
Work makes your health worse	9	11	32	63	164
	3.23%	3.94%	11.47%	22.58%	58.78%
You can't work at the same pace as other people	45	37	37	45	115
	16.13%	13.26%	13.26%	16.13%	41.22%
You need time off work predictably, e.g. for medical appointments	32	42	57	52	98
	11.39%	14.95%	20.28%	18.51%	34.88%
You need time off work unpredictably, e.g. due to a flare-up	14	10	13	52	191
	5.00%	3.57%	4.64%	18.57%	68.21%
You predictably need breaks whilst at work (e.g. scheduled rest breaks)	28	27	54	56	115
	10.00%	9.64%	19.29%	20.00%	41.07%
You unpredictably need breaks whilst at work (e.g. epilepsy, mental health issues)	38	21	35	48	137
	13.62%	7.53%	12.54%	17.20%	49.10%

14. What aspects of your last job can you no longer do, due to your health condition(s)?

	I can still do this	I can do this sometimes	I can no longer do this at all	I never used to do this
Managing people below you	31	75	76	77
	12%	29%	29.30%	29.70%
Talking to or working with colleagues	60	136	62	2
	23.10%	52.30%	23.80%	0.80%

Talking to clients, customers or service users	47	113	84	17
	18%	43.30%	32.20%	6.50%
Cognitively challenging work	43	108	91	16
	16.70%	41.90%	35.30%	6.20%
Physically challenging work	18	46	147	49
	6.90%	17.70%	56.50%	18.80%
Emotionally challenging work	25	80	125	30
	9.60%	30.80%	48.10%	11.50%
Being on your feet or walking	26	80	128	27
	10%	30.70%	49%	10.30%
Sitting at a desk or other workstation	53	112	72	18
	20.80%	43.90%	28.20%	7.10%
Driving	25	66	55	112
	9.70%	25.60%	21.30%	43.40%
Small movements	77	136	29	16
	29.80%	52.70%	11.20%	6.20%
Larger movements	33	79	110	34
	12.90%	30.90%	43%	13.30%

15. If you have had to leave a previous job due to your health condition(s), please describe in your own words why this was the case.

Employer related	no adaptations/adjustments made (but could have been)	21	13.6%
	lack of understanding/no support	14	9.1%
	bullying	13	8.4%
	required to leave due to condition	12	7.8%
	discrimination	11	7.1%
	pressurised - organisation too demanding	3	1.9%

Work related	can't do specific job	39	25.3%
	lots of time off/unpredictably off work	26	16.9%
	can't do any job	21	13.6%
	made physical health worse	13	8.4%
	made mental health worse	13	8.4%
	made health (unspecified) worse	11	7.1%
	couldn't cope with pressure/stress	7	4.5%
	job not adaptable/no alternative	6	3.9%

Support/adjustments offered but were insufficient	adaptations	5	3.2%
	flexible working/part time	5	3.2%
	unspecified	2	1.3%
	access to work	1	0.6%

Other	self/clients/colleagues at risk	5	3.2%
	family issues	4	2.6%

Physical symptoms	physical pain	32	20.8%
	fatigue	28	18.2%
	Physical - other	22	14.3%
	cognitive	21	13.6%
	Physical – Not otherwise specified	15	9.7%
	wheelchair dependant or restricted mobility	14	9.1%
	ME/fibro	12	7.8%
	incontinence	8	5.2%
	epilepsy/blackouts/seizures	7	4.5%
	time off	4	2.6%
	blind/visual impairment	3	1.9%

Mental symptoms	Stress/nervous breakdown	23	14.9%
	depression	22	14.3%
	anxiety	19	12.3%
	Mental - NOS	17	11.0%
	PTSD	8	5.2%
	Panic attacks	7	4.5%
	Mental - other	6	3.9%

16. Please describe in your own words what it is about your health condition(s) that makes work difficult for you.

fluctuating condition - unreliable, inconsistent, can’t work to deadlines	43	22.5%
could be self employed	1	0.5%

physical symptoms	fatigue	83	43.5%
	Physical - other	71	37.2%
	pain	64	33.5%
	cognitive	59	30.9%
	mobility	34	17.8%
	unable to sit/stand for long	23	12.0%
	fibro/me/cfs	20	10.5%
	incontinence	13	6.8%
	sleep disorder	12	6.3%
	vomiting/nausea	9	4.7%
	migraine/severe headache	9	4.7%
	Not otherwise specified	4	2.1%

Mental symptoms	anxiety	44	23.0%
	depression	29	15.2%
	social phobia/agoraphobia	25	13.1%
	other	22	11.5%
	Not otherwise specified	9	4.7%
	panic attacks	8	4.2%
	stress	8	4.2%
	mood disorder	3	1.6%

Ability to work	activity/work makes health worse	28	14.7%
	Employers' attitude, no support or adjustments	23	12.0%
	can't work at all	8	4.2%
	employers won't take on	6	3.1%

outside of work support	time to manage condition	10	5.2%
	travel	7	3.7%
	home support	5	2.6%

In work support	other adjustments	7	3.7%
	part time	6	3.1%
	work from home	5	2.6%
	flexibility	2	1.0%

17. If you had the right job and support, could you do some work? Include work from home or self-employment in your answer. This is not about requiring you to work, but about what you could or would like to do if you were given all the support you need.

	#	%
Yes, I could work full-time	28	10.30%
Yes, I could work part-time	120	44.10%
No, I could not work at all	124	45.60%

18. What stops you working in the right job with the right support? Please select all that apply.

	#	%
Travelling to work is too difficult	165	62.30%
I can't find a suitable job to apply for	135	50.90%
I can find jobs that I could do if they were at lower hours, but none at the hours I could do	59	22.30%
I can find jobs I could do if I were allowed to work flexibly, but this isn't offered	81	30.60%
I apply for jobs but employers won't take me	56	21.10%
I can't get the support I would need with the work/job role itself	87	32.80%
I can't get the support I would need in the workplace	101	38.10%
I can't get the support I would need at home (including finding other people to take on home or caring responsibilities that you currently do)	71	26.80%
Lack of confidence	105	39.60%
Lack of motivation	50	18.90%
Lack of recent job-applicable skills	56	21.10%
My health problems means I can't use the skills I have (e.g. if you used to be a builder, and back pain prevents manual work)	168	63.40%
Other	75	28.30%

19. What support would you need to work? Please select all that apply.

	#	%
Paid disability leave	129	52.40%
Relaxed disciplinary procedures	108	43.90%
Support worker	69	28%
Extra time to learn the job or new tasks	86	35%
Physical adaptations to the workplace	99	40.20%
Specialist software	45	18.30%
Specialist tools	44	17.90%
Access to better physical healthcare	182	74%
Faster access to physical healthcare	87	35.40%
Access to better mental healthcare	101	41.10%
Faster access to mental healthcare	82	33.30%
Transport	112	45.50%
Flexible hours	175	71.10%
Annualised hours	47	19.10%
Work from home	161	65.40%
Supportive employer	176	71.50%
Supportive colleagues	157	63.80%
Self-employment	60	24.40%
Other	63	25.60%

20. What support do you need to find work? Please select all that apply.

	#	%
Support to develop CV and interview skills	51	22.40%
Support to develop workplace skills	46	20.20%
Support to develop motivational skills	44	19.30%
Support with confidence building	70	30.70%
Access to retraining	78	34.20%
Access to volunteering opportunities or experience	45	19.70%
Job broker (job brokers find suitable employers, jobs and support)	59	25.90%
Specialist employment adviser	83	36.40%
Opportunity for a phased return to work	85	37.30%
Not being subject to conditions or sanctions in order to receive ESA	150	65.80%
Supportive employer	134	58.80%
Access to better physical healthcare	94	41.20%
Faster access to physical healthcare	78	34.20%
Access to better mental healthcare	93	40.80%
Faster access to mental healthcare	81	35.50%

Other	63	27.60%

21. To what extent does each of the following impact your ability to work, or to find work?

	Not at all	A little	Somewhat	Quite a lot	A lot
Employers won't make reasonable adjustments	23	24	35	38	114
	9.80%	10.30%	15%	16.20%	48.70%
Employers are inflexible about the work environment and how work is carried out	17	21	27	35	138
	7.10%	8.80%	11.30%	14.70%	58%
Employers think people with long-term illness are less productive	22	8	18	50	137
	9.40%	3.40%	7.70%	21.30%	58.30%
Employers are scared of employing people with long-term illness	19	7	13	47	149
	8.10%	3.00%	5.50%	20.00%	63.40%
Employers think it is too expensive to employ people with long-term illness (e.g. to cover sick leave)	19	7	14	40	154
	8.10%	3.00%	6.00%	17.10%	65.80%
Employers discriminate against people with long-term illness	21	10	17	48	136
	9.10%	4.30%	7.30%	20.70%	58.60%
Employers don't do enough to combat bullying, harassment and a lack of understanding of disabled people in the workplace	35	14	34	40	107
	15.20%	6.10%	14.80%	17.40%	46.50%
Employers say they can't get or do not have the insurance they would need	72	24	25	36	67
	32.10%	10.70%	11.20%	16.10%	29.90%
You haven't been able to get the healthcare you need	51	28	22	34	87
	23%	12.60%	9.90%	15.30%	39.20%
You have experienced delays in getting the healthcare you need	49	16	27	39	94
	21.80%	7.10%	12%	17.30%	41.80%

22. Please describe in your own words what support you need to work.

can't work at all	44	31.9%
no/can't find jobs that match needed support	7	5.1%

Health care	Need faster/better treatment (unspecified)	18	13.0%
	Better mental health treatment	10	7.2%
	Better physical health treatment	5	3.6%
	GP needs to be more helpful	3	2.2%

Employer	be supportive/understanding	31	22.5%
	not refuse interview	4	2.9%
	better/follow Occupational Health advice	3	2.2%
	recognise abilities/desire to work	3	2.2%
	not consider overqualified	2	1.4%
	overlook gaps in CV	2	1.4%
	better understanding, not one size fits all approach	1	0.7%

Workplace modifications	ergonomic chair/desk	11	8.0%
	assistive technology	6	4.3%
	disabled access eg parking	5	3.6%
	ergonomic mouse/keyboard	2	1.4%

Job modifications	flexible working	30	21.7%
	home working	29	21.0%
	commissioned outcomes/no deadlines/pressure	15	10.9%
	limited hours	13	9.4%
	staggered start/longer training	6	4.3%
	rest breaks	5	3.6%
	quiet place to work (or earphones)	3	2.2%

Outside support	PA/carer/support worker	13	9.4%
	travel assistance	9	6.5%
	home help	8	5.8%

Government help	continued benefits	7	5.1%
	help job search	6	4.3%
	self employed - benefits issue	5	3.6%
	fund to retrain	4	2.9%
	better jobcentre advice/support	3	2.2%
	impartial/fair advisor no targets	3	2.2%
	advocate	2	1.4%
	better housing space, one floor	2	1.4%
	job - no targets	1	0.7%

23. In your opinion, what information is relevant to assessing an individual's ability to work, other than health factors?

	Not important	Slightly important	Medium importance	Important	Very important
Skills and experience	25	27	38	74	92
	9.80%	10.50%	14.80%	28.90%	35.90%
Qualifications	36	38	78	56	47
	14.10%	14.90%	30.60%	22%	18.40%
Whether past qualifications, skills and experience can be used given current health	14	9	39	66	128
	5.50%	3.50%	15.20%	25.80%	50%
Time since last in work	39	57	53	52	53
	15.40%	22.40%	20.90%	20.50%	20.90%
Time until retirement age	60	44	41	51	58
	23.60%	17.30%	16.10%	20.10%	22.80%
Ability to commute to work	7	11	39	61	137
	2.70%	4.30%	15.30%	23.90%	53.70%
What work is available in the local employment market	14	9	24	51	156
	5.50%	3.50%	9.40%	20.10%	61.40%
Whether you would need to get someone to carry out home duties if you were in work	34	19	34	55	111
	13.40%	7.50%	13.40%	21.70%	43.90%
Whether you would need someone to help you with caring responsibilities	46	16	34	48	110
	18.10%	6.30%	13.40%	18.90%	43.30%
Whether you would need more support with personal care	24	12	22	48	147
	9.50%	4.70%	8.70%	19%	58.10%

24. In your opinion, which of the following areas covered by the Work Capability Assessment (WCA) are important to the health-related ability to work?

	Not important	Slightly important	Medium importance	Important	Very important
Mobility	2	10	23	51	171
	0.78%	3.89%	8.95%	19.84%	66.54%
Ability to sit and stand	6	8	22	43	175
	2.36%	3.15%	8.66%	16.93%	68.90%
Dexterity (using hands and arms)	4	6	24	56	165
	1.57%	2.35%	9.41%	21.96%	64.71%

Sight	6	10	27	76	136
	2.35%	3.92%	10.59%	29.80%	53.33%
Hearing	6	15	31	76	125
	2.37%	5.93%	12.25%	30.04%	49.41%
Continence	5	12	20	57	160
	1.97%	4.72%	7.87%	22.44%	62.99%
Staying conscious (e.g. epilepsy, narcolepsy)	3	5	13	34	199
	1.18%	1.97%	5.12%	13.39%	78.35%
Social difficulties (coping with others' behaviour; behaving and responding appropriately yourself)	3	7	14	53	178
	1.18%	2.75%	5.49%	20.78%	69.80%
Being in a workplace or getting to work (coping with being in places other than your home)	2	7	12	53	182
	0.78%	2.73%	4.69%	20.70%	71.09%
Learning new tasks	6	12	30	82	126
	2.34%	4.69%	11.72%	32.03%	49.22%
Starting and completing tasks	5	11	17	78	145
	1.95%	4.30%	6.64%	30.47%	56.64%
Coping with change	4	8	20	71	154
	1.56%	3.11%	7.78%	27.63%	59.92%
Awareness of hazards	2	6	11	50	186
	0.78%	2.35%	4.31%	19.61%	72.94%

25. In your opinion, which of the following areas that are not explicitly addressed by the Work Capability Assessment (WCA) are important to the health-related ability to work?

	Not important	Slightly important	Medium importance	Important	Very important
Pain	1	3	5	33	219
	0.38%	1.15%	1.92%	12.64%	83.91%
Fatigue	1	0	5	34	220
	0.38%	0.00%	1.92%	13.08%	84.62%
Ability to concentrate and think clearly	1	0	9	35	215
	0.38%	0.00%	3.46%	13.46%	82.69%
Ability to work under pressure	4	3	25	58	168
	1.55%	1.16%	9.69%	22.48%	65.12%
Ability to reliably work to deadlines	4	5	18	65	166
	1.55%	1.94%	6.98%	25.19%	64.34%

Psychological distress	1	2	10	40	206
	0.39%	0.77%	3.86%	15.44%	79.54%
Time away from work predictably, e.g. for medical appointments	4	4	22	50	178
	1.55%	1.55%	8.53%	19.38%	68.99%
Time away from work unpredictably, e.g. for flare-ups	2	1	5	40	210
	0.78%	0.39%	1.94%	15.50%	81.40%
Time off predictably while at work, e.g. for scheduled rest breaks	4	5	30	60	160
	1.54%	1.93%	11.58%	23.17%	61.78%
Time off unpredictably while at work, e.g. due to epilepsy, narcolepsy, loss of continence	2	3	7	33	211
	0.78%	1.17%	2.73%	12.89%	82.42%

26. Which of the following do you agree are acceptable professions to carry out assessments for a sickness benefit?

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
Your own GP	5	10	15	51	182
	1.90%	3.80%	5.70%	19.39%	69.20%
Any doctor (not one who treats you)	40	57	56	78	27
	15.50%	22.09%	21.71%	30.23%	10.47%
A specialist in your condition (including a specialist nurse, physiotherapist, psychotherapist)	11	9	19	76	149
	4.17%	3.41%	7.20%	28.79%	56.44%
Any medic (including non-specialist nurses or physiotherapists, or those specialised in a condition other than your own/your main condition)	130	86	24	9	9
	50.39%	33.33%	9.30%	3.49%	3.49%
An occupational therapist (OTs are trained to assess functional ability)	68	63	56	52	19
	26.36%	24.42%	21.71%	20.16%	7.36%
A job consultant (job consultants are trained to understand the job market)	178	45	24	8	3
	68.99%	17.44%	9.30%	3.10%	1.16%

A community-based worker, such as a social worker	129	60	45	19	5
	50.00%	23.26%	17.44%	7.36%	1.94%

27. In your opinion, who should be allowed to contribute information which may affect your assessment?

	Never	At your initiative only	At the assessor's initiative only	At either your or the assessor's initiative	Always
Your GP	1	26	1	30	204
	0.38%	9.92%	0.38%	11.45%	77.86%
A different medic/health care provider (other than your GP)	22	89	3	69	73
	8.59%	34.77%	1.17%	26.95%	28.52%
A social worker/social care provider	20	108	7	60	62
	7.78%	42.02%	2.72%	23.35%	24.12%
Family and friends	10	102	3	58	85
	3.88%	39.53%	1.16%	22.48%	32.95%
The professional (either health or social care) most involved in your care	2	37	3	39	180
	0.77%	14.18%	1.15%	14.94%	68.97%

28. Which of the following features would you consider to be important or necessary to a good assessment?

	This definitely shouldn't happen	It might be unhelpful if this happened	It doesn't matter if this happens or not	It might be helpful if this happened	This definitely should happen	Not sure/ Don't know
Medical evidence collected and read before the assessment	4	0	0	14	237	8
	1.52%	0.00%	0.00%	5.32%	90.11%	3.04%
Several meetings with the assessor to discuss what you can do, before a decision is made	19	32	8	106	73	21
	7.34%	12.36%	3.09%	40.93%	28.19%	8.11%

Opportunity for you to read the assessor's report and say or write down where you disagree and why, before a decision is made	3	1	0	25	222	10
	1.15%	0.38%	0.00%	9.58%	85.06%	3.83%
The person who decides on your case is the same person as the one who carries out the assessment	22	29	17	61	92	38
	8.49%	11.20%	6.56%	23.55%	35.52%	14.67%
There shouldn't be a face-to-face discussion, it should just be on paper	41	54	32	68	31	33
	15.83%	20.85%	12.36%	26.25%	11.97%	12.74%
The person who carries out the assessment should be the person who works with you to support work (if work is at all possible, and including voluntary work or home responsibilities)	30	19	31	90	48	42
	11.54%	7.31%	11.92%	34.62%	18.46%	16.15%
The assessment should explore ways to help you move into work before a decision is made	31	27	23	81	71	27
	11.92%	10.38%	8.85%	31.15%	27.31%	10.38%
The assessment should have to identify jobs you could do if you are to be found fully fit for work	24	12	14	54	129	26
	9.27%	4.63%	5.41%	20.85%	49.81%	10.04%

29. In general, do you think people in the following groups should be on Jobseeker's Allowance (JSA), on ESA with some requirement to move towards work, or on ESA with no requirements at all? This question is not about supporting ESA as it is or the Work-Related Activity Group; it is about exploring the extent to which some people may be able to move towards work, and where the threshold between ESA and JSA might be.

	Jobseeker's allowance	ESA, in a general group with requirement to engage	ESA, in a specific group tailored for this group of people, with requirement to engage	ESA, without any requirements	Don't know/Not sure
People who are able to work full-time, but only in a limited range of jobs and with support or adjustments (e.g. people who have been blind since birth)	12	16	146	62	23
	4.63%	6.18%	56.37%	23.94%	8.88%
People who could work part-time (e.g. people with mild to moderate fatigue)	16	43	125	52	23
	6.18%	16.60%	48.26%	20.08%	8.88%
People who could work in the future if they had re-training, rehabilitation, work experience, volunteering or a phased return to work (e.g. people whose condition means they can no longer work in the area they used to work in)	22	41	119	55	22
	8.49%	15.83%	45.95%	21.24%	8.49%
People who have a self-limiting illness or condition	8	32	37	139	42
	3.10%	12.40%	14.34%	53.88%	16.28%
People who have a progressive illness	1	0	13	229	15
	0.39%	0.00%	5.04%	88.76%	5.81%
People who have a terminal illness	2	0	6	236	14
	0.78%	0.00%	2.33%	91.47%	5.43%

30. Finally, imagine you had a clean slate and could design a sickness benefit from scratch - what should it look like? Aspects to consider include: (a) The reasons people should be judged as able or unable to work; (b) Who does the assessments, who makes the decisions and what evidence they ask for; (c) What groups, conditions, sanctions or incentives should be used (if any); and (d) how sickness benefits should link in with Universal Credit, which may involve requirements to look for small numbers of hours of work.

Critique of the current system	Negative view of claimants	16	10.7%
	Assumption of fraud	11	7.4%
	Assessors lie or trick claimants into failing, an attempt to cut numbers	9	6.0%
	criticism of the tasks/questions used to assess	3	2.0%
	the current job support is inadequate	6	4.0%

Old system	there was little/less wrong with the old system	11	7.4%

Breaks down as: 7: the old system was better

4: the old style disability employment advisors were good

Assessors and decision makers	Assessor should be own GP/consultant	21	14.1%
	Assessor should be a specialist with knowledge of the condition(s)	28	18.8%
	Assessor should be a qualified professional with the nhs	12	8.1%
	Assessor should not be DWP/ATOS/contractor or anyone with number-cutting targets	16	10.7%
	GP/consultant should be involved before a decision is made	9	6.0%
	GPs don’t want to be a gatekeeper	1	0.7%
	GP as assessor could undermine the relationship with the claimant	2	1.3%
	Assessor should be an occupational therapist or specialist with knowledge of working conditions	4	2.7%
	Decision should be made by two or more people	7	4.7%
	The assessor should also be the decision maker	6	4.0%

Evidence	more weight on GP/medical evidence	18	12.1%
	evidence from all consultants involved with the claimant should be considered	21	14.1%
	DWP should justify their decision and not be permitted to dismiss evidence. In particular, not finding someone fit for work against a GP sicknote	12	8.1%
	DWP should ask and pay for evidence, not leaving it to the claimant to provide	4	2.7%
	evidence gathered should be sufficient to make a fair decision	1	0.7%
	claimant should be allowed to send in evidence first but not required to do so	1	0.7%

Factors to consider	better consideration of fluctuating conditions	9	6.0%
	better consideration of chronic illness	17	11.4%
	better consideration of mental health	22	14.8%
	better consideration of pain and fatigue	11	7.4%
	holistic assessment - all circumstances taken into account	24	16.1%
	Assessment should not be a tick-box or checklist of tasks	12	8.1%
	Job market conditions and employers' view should be considered	14	9.4%
	progressive condition	4	2.7%
	unfit if work makes health worse	3	2.0%
	impact of work/commute on life	4	2.7%
	full medical history	1	0.7%
	impact of medical appointments on ability to work	1	0.7%

Procedure	Avoid iface-to-face interviews wherever possible, decision based on reports and evidence	9	6.0%
	minimise stress/damage from process	7	4.7%
	process should be fair	4	2.7%
	guidance on information required	3	2.0%
	shorter forms	3	2.0%
	more time to fill in forms and get evidence in	2	1.3%
	see report before decision	2	1.3%
	longer interviews	1	0.7%
	quicker and easier process	1	0.7%
	recorded assessments	1	0.7%
	complaints procedure	1	0.7%

Categories	2 categories - no recovery likely and recovery likely	10	6.7%
	more categories - permanent disability, long-term sick and short-term sick	10	6.7%
	Disability is different to sickness	2	1.3%

Reassess	permanent award: permanent disability; progressive, terminal or chronic illness	22	14.8%
	reassess only those expected to recover.	7	4.7%
	permanent over certain age	1	0.7%
	Claimant's GP to decide when to reassess	2	1.3%
	For chronic illness, a GP letter should be sufficient reassessment to confirm claimant is still sick	1	0.7%

Level	Benefit should be higher than it currently is	10	6.7%
	Part-time, self-employed or volunteer: still get benefits	16	10.7%
	trialling work should be possible without jeopardising benefits	21	14.1%
	citizens income	9	6.0%
	ESA should be paid until the application and any appeals are complete	2	1.3%
	no time limits	2	1.3%

Support	Good DEAs	29	19.5%
	tailored support	16	10.7%
	retraining support	14	9.4%
	no ‘requirement to engage’	14	9.4%
	meet claimant’s health needs before expecting work	9	6.0%
	opt-in for support to work if claimant wants it	13	8.7%
	No sanctions	47	31.5%
	Incentives/bonus for working	12	8.1%
	consider impact on claimant’s health of the ‘requirement to engage’	6	4.0%
	More Access to Work	4	2.7%
	Find fit for work only if assessor can place in work	1	0.7%
	don’t expect work without significant support	6	4.0%

Support - employers	Miscellaneous: action to encourage employers to take on claimants	13	8.7%
	encourage flexible working	12	8.1%
	more adjustments by employers needed, eg not just wheelchair accessible	5	3.4%
	work needs to be suitable	2	1.3%

UC	exclude sickness benefit from UC	5	3.4%
	no UC	4	2.7%

other		52	34.9%

The Authors

Stef Benstead is an independent disability and social security researcher. She has previously worked with the Spartacus Network and has been lead author on a number of their reports. She is particularly concerned by the inability of current disability and sickness benefits to adequately assess people with chronic illness, and is interested more widely in inequality and its impact on people, countries and human rights. Stef brings personal experience to her research through her own medical conditions.

Emma Nock contributed to the most recent Spartacus Network report, *Crippling Choices*, which responded to the UK government's consultation on the use of aids and appliances for people wishing to claim Personal Independence Payment. She has previously worked for the Red Cross and for the Sanctuary Housing Association. She brings personal experience to her work, both through what she has seen in her previous professional roles, and through her own physical health conditions.

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About Ekklesia

Founded in 2002, Ekklesia is a public policy think-tank that explores the changing nature of the relationship between politics and beliefs in a plural world. Committed to social justice, peacemaking, environmental sustainability and new economy, it seeks to combine transformative Christian thinking about public life with ideas and insights from a range of allies beyond the Christian tradition. Ekklesia has published and co-published a number of significant reports on welfare and disability in recent years, giving priority to the voice, experience and expertise of people living at the cutting edge of these issues. www.ekklesia.co.uk

Further Reading

Reforming welfare: moving beyond the austerity mentality, by Bernadette Meaden (Ekklesia, May 2015). http://www.ekklesia.co.uk/node/21665

Social Security and the 'shrinking state', by Savitri Hensman (Ekklesia, May 2015). http://www.ekklesia.co.uk/node/21664

The DWP's Fit for Work Service: Who benefits?, by Bernadette Meaden (Ekklesia, October 2014). http://www.ekklesia.co.uk/node/20979

Beyond the Barriers: ESA, the Work Programme and recommendations for a new system of support, by Spartacus Research (co-published by Ekklesia, May 2014). http://www.ekklesia.co.uk/beyondbarriers

Welfare that Works: Employment and Support Allowance (ESA), by Stef Benstead (Spartacus Research / Ekklesia, December 2013). http://www.ekklesia.co.uk/node/19670

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