

A landscape photograph showing a dirt path leading through a green field towards a line of trees under a blue sky with white clouds.

# Replacing Employment and Support Allowance

Part One: Support Needs  
of People With Chronic Illness

by **Stef Benstead and Emma Nock**

This Executive Summary should be read in association with the full report, available for download at:

[www.ekklesia.co.uk/ESareportPartOne](http://www.ekklesia.co.uk/ESareportPartOne)

'Support Needs of People with Chronic Illness' has been researched and written by Stef Benstead and Emma Knock. It is the first of a three-part project on Replacing Employment and Support Allowance, and is published by the independent think-tank Ekklesia.

## Introduction

Over the last few decades, 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). Countries have variously tightened eligibility criteria, reduced payments and increased support to help individuals prepare for and keep work (ibid.). The UK originally tightened the eligibility criteria in 1995 with the introduction of Incapacity Benefit, and then tightened them further in 2008 with the introduction of Employment and Support Allowance. ESA also reduced the level of benefit and increased the conditionality for a subset of claimants deemed capable of work-related activity. At the time, it was anticipated that this would be the largest group of ESA claimants.

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.

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.

## This Survey

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. We focused on chronic illness as this group of people are not well represented at the policy level, and consequently are amongst the least well-served by the Work Capability Assessment.

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. The majority of questionnaires were completed online and the survey was promoted via social media. 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)

## Work Ethics

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, 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.

## **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.

It was felt that the WCA as it stands cannot capture these issues well, either from the point of view of the claimant or that of the employer. 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 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.

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

## **Support Needed**

A common theme throughout the questions was the need for both better and faster healthcare. Previous employment programmes for people with chronic illness, such as Pathways to Work, have done well when they have included the NHS, albeit aimed 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).

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 of 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 and Mercer, 2005; Dekkers-Sanchez, et al., 2010).

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 in those who live in rural or more deprived areas, where jobs are on average further away; 62% said that the impact of commut-

ing 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).

A significant difficulty was caused by having skills, but being unable to use them due to a health condition: for example, if a person was engaged in a manual trade which pain or fatigue now renders impossible. 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). At the same time, individuals could be unable to get higher level jobs due to the impact of their illness, whilst being over-qualified for lower-level jobs.

## **Employers**

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%).

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 supportive employers (71.5%) and supportive colleagues (64%).

Work was more likely to be possible when it was flexible (71%), undertaken from home (65%) and more similar to a commissioned outcomes system than the standard model of work. This generally works out as meaning working at random hours for random lengths of time, depending on the moment-to-moment capacity. However, this can be difficult for employers, as it means that unpredictable amounts of work are being performed each week, with greater likelihood of an employee missing deadlines, and increased costs associated with managing unpredictable workflow.

Some respondents also indicated a need for paid disability leave, to relieve financial pressure on the employee, and relaxed disciplinary procedures, to improve job security. Again, these are likely to be costly to employers and may render some individuals with chronic illness unemployable unless the government provides financial assistance to the employer to compensate for these associated costs. As it is, respondents already experience problems from adjustments not being provided, even though this is a legal obligation on employers. The government may need to enforce the provision of reasonable adjustments more thoroughly.

## **Conclusion**

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.

### **The next stage in this research**

For the next stage of the project, Ekklesia is running 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.

## 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.

## 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.ekkleisia.co.uk](http://www.ekkleisia.co.uk)

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