

The benefits scandal

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The government is withdrawing the support that enables disabled people to work, while simultaneously arguing that more of them should be working.

Despite significant progress in earlier decades towards enshrining legal rights and protection for disabled people, beginning with Lord Morris's Chronically Sick and Disabled Person's Act (1970), the future of the disabled community now appears uncertain. The drive towards independent living, and efforts to establish rights to access businesses, services, transport, education and employment through the Disability Discrimination Act (now Equalities Act), are now being thwarted by the proposed cuts. Prior to the 2010 election the outlook was already stormy, in the context of rising hate crimes and the demonisation of welfare claimants by a slavering media egged on by politicians - with one eye firmly on the welfare balance sheet and the other determinedly closed to the consequences of their actions.¹ Then, within months of their election, the Coalition government were championing and cheering on a round of cuts that are increasingly devastating in their impact upon disabled people. Because of this, a new generation of sick and disabled people have now been radicalised into activism.

Two perceptions of sickness and disability pervade mainstream thinking. On the one hand there are the lazy scrounging scum, perfectly able to work if they choose, draining resources from an already overburdened taxpayer; on the other there are the deserving claimants, pitiful creatures, who will be provided for with free cars, bungalows and holidays as compensation for their lot. Neither image reflects reality, but the former continues to be cemented in the public consciousness, fed by a diet of moral outrage based upon statistics that the DWP themselves have been forced to admit give a distorted picture.² As to the latter

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image - it is based on a misconception amongst the general public that, should they become sick or disabled, the state will step in and willingly provide all that is needed. The dominance of these contradictory and inaccurate ideas helps to explain why the savage cuts that are being championed in the name of reform are going largely unchallenged. It seems that, whilst most of the public can immediately understand the importance of saving forests for all our futures, an understanding of the importance of sickness and disability benefits and services tends to be confined to those who are directly affected.

However, the introduction of Disability Living Allowance (DLA) in 1992 was an acknowledgement that sickness and disability bring with them additional and unavoidable financial burdens. But Thatcher's drive towards community care during the 1980s - initially welcomed as a positive step by the disability rights movement - was never sufficiently funded, and this meant that part of the effect of the new DLA was to transfer to individuals funding that had previously gone to institutions, as people moved into independent living. Separated into two components, for mobility and care, DLA was an important part of the fledgling personalisation agenda. This perception has therefore always been something of a mixed blessing, but it did at least allow some people to live more independently.

Within months of their 1997 election victory New Labour had announced plans to dramatically curb eligibility to disability benefits, on the basis that spending had doubled and must be curbed. Charities greeted this announcement with outrage, and pointed to the legitimate reasons for the increases in costs, which were being ignored by government; these included medical advances, the costs of community care, and the success of efforts to encourage take-up of these benefits. One noteworthy protest involved people in wheelchairs chaining themselves to the Downing Street gates and throwing red paint around, to symbolise 'Blair's blood'.³ Soon after, the first plans for reforming disability benefits were quietly shelved.

During the following decade a new generation of disabled people - born with an expectation of their right to live independently - began to come of age, and they were joined by larger numbers of people who had recently become sick and disabled in the course of their working, tax-paying lives. Together they constituted a generation who had not known the horror of imprisonment in institutions. Having lived more freely for a while, disabled people were at first slow to recognise the threats being made to their independence. However, New Labour had not

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given up on their 'reforms' of welfare provision, and in October 2008, after a long period of preparing the ground, previous disability benefits were replaced by a new Employment Support Allowance (ESA), whose eligibility criteria seemed deliberately designed to exclude large numbers of people from benefits.

High unemployment throughout the 1980s had also undoubtedly contributed to the numbers of people claiming Incapacity Benefit (IB); this was because mostly male, older claimants, who were far more likely to have industrial injuries or sickness from their working years, had been deliberately directed towards incapacity benefit as a way of reducing unemployment figures.⁴ But this group were then seized upon by politicians as characterising the entire claimant group, and were used to justify major efforts to reduce the number of IB claimants, in the first instance in measures put forward by John Hutton. Then, during Peter Hain's stewardship, the Department of Work and Pensions used research carried out at Cardiff University, part-funded by the American private insurance company Unum, to move towards a 'biopsychological' model of sickness and disability.⁵ Deeply concerned by the rise in insurance claims for sickness and disability that lacked clear 'biological markers', the basic premise of the biopsychosocial model was to reclassify the concept of sickness preventing work: the argument was that in reality it was the individual's perception of their own sickness that was leading them to believe themselves unfit for work. They believed that this incorrect perception could be easily be corrected, and on this basis they would be able to reduce the number of successful claims - from both state and private insurance providers.

However, it was James Purnell's leadership at the DWP which first propelled this new group of sick and disabled claimants on their journey towards activism. The premise of ESA had initially seemed reasonable - that some people were so sick and disabled they should be supported unconditionally, whilst others might be capable of some work under the right conditions and with the right support. But the means by which people were to be assessed, and the widespread introduction of sanctions to this vulnerable group, soon revealed its true motives, which, fundamentally, were aimed at reducing the number of claimants, based on the false idea that substantial numbers of claims were fraudulent. By 2007 the benefit scrounger rhetoric was increasing, and campaigns such as 'no ifs, no buts, benefit fraud is a crime' were becoming popular. But the MPs' expenses scandal in 2009, which included the revelation of claims by Purnell for large sums of money for his grocery

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bills - which he claimed at a monthly rate higher than unemployment benefit levels - encapsulated the hypocrisy of New Labour thinking for sick and disabled people, and made Purnell a figure of fury as well as fear, thereby helping to sow the seeds of more recent activism.⁶

There is a distinct irony in current disability rights politics: determined to create his Big Society, David Cameron's only true step towards this has been to unify the disabled community, who traditionally have been concerned with emphasising the different needs and identities of each group. Unfortunately there are no political allies on the horizon. Betrayed, abandoned and enraged by the welfare policies of the New Labour years, disabled people already had our backs against the wall, and the savagery of the cuts outlined in the comprehensive spending review are pushing us over the edge. Respect for fellow members of our disabled community at one time meant that Cameron had an easier ride on disability issues, because of his personal experience as a son and father of a disabled person. But his willingness to use these experiences as a campaign tactic has backfired, creating a deep anger and visceral mistrust towards him personally.

The effects of deficit reduction on the disabled

Out of a total planned reduction in public spending of approximately £90 billion, the cuts initially outlined by George Osborne that affect sick and disabled people are estimated to total £9 billion: in other words, ten per cent of the overall cuts burden will fall upon the most vulnerable in society.⁷ These cuts are so wide ranging that it is impossible to provide a truly comprehensive list, particularly as sick and disabled people are more heavily reliant than most on NHS and local authority services; for the purposes of this article only those cuts directly affecting employment prospects will be considered.

Sick and disabled people feel that we are living in a horror story worthy of Poe, as more and more of the vital supports we rely upon for daily life are either removed or made significantly more difficult to access. Time and energy that is already limited by health conditions will now have to be spent upon increasingly fruitless applications for support, thus creating additional barriers to the possibility of employment.⁸ There has been no consideration of this conundrum in the government's current plan to transfer a million people from sickness and disability

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income replacement benefits into the totals for jobseeker allowance. If suitable accommodation, equipment and support were freely available, sick and disabled people would feel more confident about the potential of employment, but with that support being withdrawn from every direction, for many of us it feels as though we are in a pit, with the walls closing in upon us and no route of escape to be found. We are being simultaneously deprived of the support we need to be able to work and demonised for not working.

Accessible social housing is also woefully inadequate and poorly allocated, so that many disabled people are forced to rent homes which are not fully accessible in the more costly private sector (approximately 78,000 households in England that include a wheelchair user survive in premises that are not fully accessible).⁹ The planned introduction of provision for an additional bedroom for a non-resident carer is a welcome step, but this extra funding will not be awarded automatically, and will be time limited in most cases to a maximum of thirteen weeks; while claimants under 35 will receive the 'shared room' rate, with exemptions only for those in receipt of middle or higher rate DLA. And the proposal to scrap DLA makes it impossible to fully assess the impact of these changes. Meanwhile the reduction of Local Housing Allowance (housing benefit), which was previously payable at the level of median average rents, but now will only be payable at the level of the bottom third, will force disabled people to rent cheaper properties that are more likely to be inaccessible. Contradictions in policy mean that DLA recipients are exempt from the caps on housing benefit, but not from the lowering of the levels of rent payable, which will have far wider effects. Suitable accessible accommodation removes many of the barriers to daily living faced by disabled people, making them more confident in considering employment, but it will be even harder to obtain once all these changes to entitlement take effect.

Mobility is another area that will be affected by cuts. The proposal to remove entitlement to the higher rate mobility component of Disability Living Allowance from state funded care home residents caused such outrage that the government have temporarily postponed the decision. But cuts to various council funded community transport schemes mean that disabled people are likely to face cost increases of more than 65 per cent, and for vastly restricted travel services.¹⁰ Much of the current transport network is inaccessible to disabled people, so that reduced funding for alternatives will further restrict travel, and have an impact upon people's

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ability to travel to and from work.

The Coalition government also intend to scrap DLA altogether, and to replace it with Personal Independence Payment (PIP), which will involve reassessing all DLA recipients from 2013, even those with lifelong degenerative conditions - at vast cost, and with the aim of further reduction to entitlement, currently estimated at 20 per cent. There are many flaws in the proposed PIP, but for the purposes of this discussion the main impact will be felt in the removal of payments for the additional costs that dealing with disability requires, which will limit the ability of sick and disabled adults to remain in work, given that the funds they use to support these additional needs are to be withdrawn.

Social care is also affected - changes to its provision, people's entitlement and charges will be affected by a number of factors, including the scrapping of the Independent Living Fund, which matched funding from local authorities for those with the highest level of support needs. Furthermore, despite government insistence that cuts in funding to local authorities should not lead to any need to reduce social care provision, areas such as Birmingham are already planning to restrict support to those that meet a threshold of care that is higher than the four bands set out in the government's fair access to care services guidance; whilst most local authorities intend to increase charges.¹¹ Yet, without assistance in performing basic daily activities such as washing, dressing, shopping or eating, considering employment is impossible for many.

Access to Work is a government scheme that provides funding for disability-related equipment in order to assist working disabled people in carrying out their roles (for example it can pay for voice activated software or specialist chairs). It supported 37,000 disabled workers in 2009-10; worryingly but not surprisingly, the figure fell to 35,830 in 2010-11.¹² Now the Sayce Report, published in June 2011, is seeking to redefine what items it is 'reasonable' to expect an employer, rather than the government, to provide for disabled employees.¹³ However, these items are frequently extremely expensive, which means that expecting employers to pay for them is likely to see a further reduction in opportunities for disabled people at work.¹⁴ The proposed list of items that employers are now to be expected to pay for will make it significantly more expensive to hire a disabled employee. Reports of disabled employees being denied access to work support have already emerged, for example one application was refused because of a stipulation that if people are

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working in senior positions they should be funded by their employer regardless of their ability to bear the costs.¹⁵

The ESA labyrinth

When it was initially proposed, one of the ideas of the Employment Support Allowance was that disabled and sick people should be helped and supported to work if they wished to do so. This was a valid and popular idea. Many sick or disabled people would indeed love to work if there was work that they could do. But in its present form the ESA is failing: it simply presents the claimant with a series of dead ends, backed up by a whole raft of sanctions and means tests that negate any realistic chance of success. It takes little account of the limitations of individual conditions, or the barriers to work that someone with a fluctuating or mental health condition may face. The capability tests that are applied to claimants are simply unfit for purpose. Currently around 40 per cent of cases go to appeal, and of these 40 per cent succeed in overturning the original decision, a figure that rises to 70 per cent for those with representation.¹⁶

To qualify for ESA, an applicant must score fifteen points or more during a Work Capability Assessment (WCA). Anyone who scores less than 15 points will be found immediately 'fit for work' and moved onto Job Seekers Allowance (JSA). Leaving aside the limitations of the point system itself (which is dealt with below), there is an evident problem for those who score up to 14 points, and live with significant functional limitations, but whose score denies them the support and assistance of the Work Related Activity Group (WRAG). (The WRAG are those who are considered fit for work if support and preparation is provided. Only those receiving enough points to be allocated to the Support Group are not required to undertake work-related activity.) Those who fail to score 15 points must now compete with able-bodied applicants for work available through the Job Centre. If an applicant is then considered unfit for work by Jobcentre staff, they are passed backwards and forwards indefinitely, between JSA and unsuccessful ESA applications. These claimants are not tracked by the DWP, so no-one really knows how many go on to find work and how many simply fall through the cracks.

To compound this, the Work Capability Assessments and the descriptors they use are widely regarded as completely inadequate. They have been comprehensively

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criticised by a recent DWP report, as well as the professor who helped design the system, various charities and the Citizen's Advice Bureau.¹⁷ They are simply not capable of assessing ability to work in any meaningful way. This leaves thousands receiving the wrong assessment, forced immediately into a workplace that they may not be ready for. Currently, 39 per cent of overall claimants are found immediately fit for work. Many of these people will have been away from the workplace for a considerable length of time, and some will have lifelong conditions.

Those placed into the WRAG (currently around 30 per cent of existing claims, and just 18 per cent of new claims) face many of the same problems. The descriptors used in the points system take no account of pain or symptoms or fatigue; they simply take a snapshot of what a person may or may not be able to do on the particular day of their assessment. Those with fluctuating conditions, which is particularly the case for those with mental health conditions or learning difficulties, are unlikely to be fairly assessed under the present system.¹⁸

With the proposed introduction of a one year time limit for those in the WRAG, almost all of the positives of ESA have been removed: after one year, whether or not their condition has improved, a claimant will now lose contributory ESA. Yet when it was designed, ESA was supposed to give sick and disabled people in the WRAG support for as long as it might take for them to enter work. The time limit removes any pretence at supporting the vulnerable, and turns ESA into a benefit that only supports conditions from which one might expect to recover within one year.

This means that if those with incurable or long-term chronic conditions are not placed in the Support Group category, thereby qualifying for unconditional long-term support, those with working partners will after one year find themselves totally dependent on them, and with no independent financial support. Currently just 7 per cent of new claimants are placed in the Support Group, meaning that thousands are faced with work sanctions that they cannot meet.

A clearly failing system breeds fear and suspicion within the disabled community, making them less likely to successfully engage with the scheme. At the same time the well publicised numbers of those suffering from its sanctions feed into the widespread assumption that those who are unwell or disabled are too lazy to work or just haven't tried hard enough. In our experience, this could not be further from the truth.¹⁹ Removing security and support will simply exacerbate many conditions, creating further pressure on the NHS and local authorities. Most people who become

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unable to work have tried many different ways of re-engaging with the workplace, but find employers unwilling to give them a chance, hours that are too long, or too rigid, or simply have to give up if their conditions worsen.

The rigidity of the current benefit system is incredibly daunting. With the proposed six-month qualifying period for DLA (it is currently three months), and a lengthy application process for ESA, claimants live in fear of giving up benefits to take a job in case they lose everything if they subsequently become unable to work again. A fairer system would offer a basic level of support to those with diagnosed conditions with a clear pathology, which could be tapered off as work is undertaken, yet readily available again if work becomes impossible or simply not financially sustainable.

Furthermore, if the system is to be rolled out to nearly 2 million people, relying on the assumption that they will be supported into work, then we should be very sure that the work programmes that have been charged with supporting claimants are operating successfully. But this is currently not the case. Pathways to Work, the programme which until very recently was responsible for assisting those on IB and ESA into work, has been found to have hardly any greater a success rate than claimants who are trying to find work on their own. Hundreds of millions of pounds have been paid out to private companies to help the sick and disabled into work, but, as Richard Disney et al explain:

Preliminary evidence from the trial evaluations suggested that these programmes [i.e. Pathways] had a significant impact on the outflow from disability insurance [i.e. IB] in the first six months of the spell, but little effect thereafter, and that the effect was focused more on some work disability conditions (mostly physical) than others (mostly mental).²⁰

In other words, those with more temporary conditions are 'helped' into work that they would have been very likely to find otherwise, whilst those with longer-term illnesses or disabilities are overwhelmingly let down by the system.

The truth is that pain, fatigue, nausea, dizziness, diarrhoea and many other symptoms are debilitating and disabling in their own right. We simply cannot wave a magic wand and expect people with serious, long-term conditions to be able to

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work in the way that an able bodied person usually can. Currently, 1 in 4 people of working age have some kind of illness or disability, and 60 per cent of them are already in work.²¹

With the rise in auto-immune conditions and long-term variable illnesses, and increased survival rates for many with congenital disabilities, the numbers of people living with long-term severe disability have risen, along with the numbers claiming DLA, whilst those claiming ESA alone have fallen.²² People are living longer, but many are being kept alive with a host of complex and expensive medications and treatments that simply were not available three decades ago. Just as we face a crisis in elderly care and pension provision, we also face a crisis of increasing levels of people living with severe disability and long-term sickness - a trend seen throughout the wealthy world. Closing our eyes to these problems won't make them go away.

Alternative ways of contributing

People living with the most severe conditions present us with an opportunity to look in a new way at the very nature of 'work' and 'contribution'. People with long-term illnesses or disabilities need an entirely different set of solutions to those who are able-bodied. A system of fully flexible working hours would potentially allow the individual to dip in and out of work as and when they were able to. The hard and fast division between 'full-time' and 'part-time' is simply too limiting. However, a system could be designed whereby this flexible work could be underpinned by a contract allowing pro-rata payments, possibly with government working in partnership with employers. Such a scheme could only operate on the basis of reliability and security when someone attempts to leave benefits and enter the workplace. It would also need to be large enough to be truly viable on a national level. At the same time, we could do much more in today's technological age to enable those with long term illnesses or disabilities to work from home in pockets of time that suit their limitations.

Those who become too ill to continue their chosen careers may be able to re-train or study for new qualifications, allowing their employer to continue employing them in different roles. However, unless this kind of support is available at the point when an illness or disability becomes too debilitating, many will simply lose their

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jobs, and then they will find it many times more difficult to get another one when the particular crisis has passed, or re-education has been completed. But as I write, education for sick and disabled people is being reduced, not extended.²³

A further option for many sick or disabled people would be to develop a hobby or small business idea into paid employment, which they would be more likely to have the confidence to do with a little support. Help to start and develop a small business, or even local business co-operatives, could remove much of the fear of failure that is inherent in starting any business, particularly when the entrepreneur is often unwell or unable to work.

Finally, government needs to engage with business, finding ways that those currently excluded from the workplace may again be included. They would do well to consider how the money already spent on welfare might be better targeted in the cases of those who wish to work but also need some time off or support in order to be able to do so. Transferring some of the welfare bill towards employers who are prepared or able to accept people with more variable limitations might remove some of the concerns that people have about fiscal responsibility. Some countries - for example Germany - mandate employers to hire a specific percentage of sick or disabled workers. Whether Britain adopts a similar scheme, or focuses on tax incentives and grants, we must start to take more note of the practicalities of employing someone with an illness or disability, and look at ways of supporting employers to do so.

It is, however, vitally important to remember that many people simply will not be able to work, and that sanctions and penalties will not create any miracle cures. But this is not to say that sick and disabled people cannot contribute in other ways. Many already volunteer or engage with their local communities, as and when they are able to. It may be unrealistic to expect those who are seriously unwell or severely disabled to fit into a traditional working model, but it is unhelpful to ignore the great contribution they can and already do make to society.

Any system that truly aims to reward responsibility, or claims to be based on fairness, must adopt a holistic approach to the idea of contribution. Those that find themselves unable to be reliably financially productive may yet be productive in many other ways. This contribution should not be ignored or dismissed, but should be part of the overall assessment of what a person can or cannot do. Politicians are currently very keen on the ideas of contribution and responsibility, but if that is

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simply taken to mean an ability to bring in a financially viable wage, it will inevitably exclude a whole sector of society with different needs and abilities.

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Notes

1. See for example www.dailymail.co.uk/news/article-1353111/Disability-benefits-Half-claimants-asked-prove-eligibility.html.
2. For recent government statistics on DLA claimants see http://statistics.dwp.gov.uk/asd/asd1/adhoc_analysis/2011/DLA_Growth_in_Caseload_FINAL.pdf.
3. See BBC news reports: <http://news.bbc.co.uk/1/hi/uk/politics/33556.stm>; <http://news.bbc.co.uk/1/hi/uk/41746.stm>.
4. For more on the myth that there are one million people on benefits who are really fit for work, see Steve Griffiths, 'The misuse of evidence in incapacity benefit reform', *Soundings* 47: www.lwbooks.co.uk/journals/soundings/articles/s47griffiths.pdf
5. For more on the biopsychosocial model, see Jonathan Rutherford, 'New Labour, the market state, and the end of welfare': www.lwbooks.co.uk/journals/articles/rutherford07.html.
6. 'Minister puts food bill on expenses', *Sunday Express*, 12.4.09.
7. See www.scope.org.uk/news/disabled-people-hit-by-welfare-cuts.

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8. See for example my own story - Kaliya Franklin, 'Being turned down for an electric wheelchair has left me dejected', *Guardian*, 4.8.11: www.guardian.co.uk/society/joepublic/2011/aug/04/denied-electric-wheelchair-nhs-criteria.
9. See www.disabledgo.com/blog/2010/08/solutions-to-housing-shortage-are-not-complicated/.
10. For an example of local cuts to community transport see www.sunderlandecho.com/news/local/end_of_the_line_for_shoppers_bus_1_2849126.
11. See www.communitycare.co.uk/Articles/2010/12/02/115939/storm-of-protest-greets-birminghams-super-critical-threshold.htm; and www.communitycare.co.uk/Articles/2010/07/01/114824/care-charges-set-to-soar-for-users-in-warwickshire.htm.
12. www.candocango.com/government-ignores-alarm-bells-as-access-to-work-figures-slump/.
13. www.dwp.gov.uk/docs/sayce-report.pdf.
14. For examples of exclusions see www.abilitymagazine.org.uk/Articles/Article-108-3.aspx.
15. www.candocango.com/fury-as-government-denies-disabled-leader-access-to-work/.
16. http://www.legislation.gov.uk/uksi/2011/228/pdfs/uksi_20110228_en.pdf
17. See www.publications.parliament.uk/pa/cm201012/cmselect/cmworpen/1015/101505.htm; www.guardian.co.uk/commentisfree/2010/jul/06/osborne-haste-undermine-incapacity-benefit-reform; www.guardian.co.uk/politics/2011/mar/09/welfare-bill-cancer-patients; www.citizensadvice.org.uk/press_20100323.
18. See Malcolm Harrington, *An independent review of the work capability assessment*, HMSO 2010, www.dwp.gov.uk/docs/wca-review-2010.pdf.
19. <http://diaryofabenefitscrounger.blogspot.com/2011/05/welfare-for-people-by-people.html>.
20. R. Disney et al, 'The baby-boomers at fifty...', in P. Gregg and J. Wadsworth (eds) *The Labour market in winter: the state of working Britain*, Oxford 2011, p67.

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21. 'Baby-boomers at fifty', see note 20.

22. See Declan Gaffney in this issue.

24. www.disabledgo.com/blog/2011/08/government-could-face-new-high-court-challenge-over-cuts/