



Replacing Employment and Support Allowance

Part 3 - Dignity and support: a new sickness benefit



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Introduction

This is the third report in a series commissioned by Ekklesia to design an alternative to ESA, WCA and the Work Programme. It presents the final recommendations for a new system of how to assess and support the work capacity of people with chronic disabling illness or disability.

The first two reports were based upon a survey conducted between October 2015 and January 2016. The reports were published in July 2016.

The first report presented the results from questions about what, if any, work the respondent could do and what support was needed in order to make that work possible.

The second report used the results on questions about how the assessment process should be carried out and what evidence and information should be included in the decision-making process. This second report presented an initial suggestion for an alternative system, and invited chronically ill and disabled people or their representatives to comment on the suitability or otherwise of the initial system.

This third and final report uses the feedback on the initial suggestion to develop an alternative to ESA and the Work Programme that has been fully produced by sick and disabled people themselves.

Previous findings

GP triage system

The system of assessment should start with triage by a person's GP. The purpose of this triage is threefold:

- To avoid dead weight, by not sending people with naturally self-limiting conditions to an assessment of capacity for work, when the individual is likely to recover and the individual's capacity for work has a high likelihood of returning to their normal level after recovery. This would include short-term injuries and infections;
- To provide early assistance to those who currently have some capacity for work if they get appropriate assistance, by referring them to an Occupational Therapist or appropriate Mental Health professional for an assessment of support needs; and
- To safeguard people who would be harmed by being required to undergo an additional assessment; for example, severe mental health crisis or severe physical illness made significantly worse by exertion.

Assessment of support: process

Based on the results from our respondents, it was proposed that a new assessment process should include the following features:

1. Medical evidence should be provided for all individuals; this is a more efficient way to get an accurate medical opinion than having to employ medics who are not involved in the individual's care;
2. The assessment should be in the format of a discussion taking place over several meetings;
3. Claimants should have the opportunity to comment on the assessor's report before a decision is made;
4. The assessor should also be the one who makes the decision on fitness for work; and
5. Reassessment need only occur for those not in regular contact with a caseworker, and should be light-touch in recognition that these are the people who are least likely to become fit for work.

Assessment of support: criteria

The criteria of fitness for work should be based on the following:

- The decision of capacity for work should include labour market competitiveness;
- 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;
- 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;
- A decision of fit for work is made if the assessor and the claimant can identify three jobs that the claimant can do without support;
- An assessment of not-yet fit for work is made if a claimant needs particular forms of support in order to be able to work. Support includes but is not limited to retraining, job brokering, technological or physical adaptations and ongoing personal support. The claimant is considered unfit for work unless and until that support is provided; and
- An assessment of unfit for work is made if there is no work the claimant could feasibly do even with support. This includes but is not limited to people who can only work a small number of hours or who can only work irregularly and/or at unpredictable times.

Next steps

The next stage of this research series was to take these proposals to focus groups of sick or disabled people, and discuss with them whether these proposals would work and if not, why not and what should be done instead.

We look first at what support sick and disabled people need. The support needs of sick and disabled people show us what it is that holds people back from work, and what needs to be provided in order to assist someone to work. We then move on to what a sickness benefit should provide. Once we know what sick and disabled people need when out of work, and what they need in order to work, we can then consider how to assess who is capable of work, who needs additional support, and who cannot work.

Chapter one: Supporting sick and disabled people

This chapter discusses in more detail the forms of support that sick and disabled people need both in their daily lives (whether or not they are capable of work) and at work (if they can work). People cannot work if they are not getting the help they need for basic living tasks such as personal care and household chores. People also need to be able to get out of their homes; and people have a right to rest, leisure and social participation outside of work. These needs and rights must be met before we can expect someone to work. Therefore, we consider what support people need outside of work, as well as what support might be needed in the workplace.

We additionally look at the DWP's and Department of Health's recent intention to label work as a health outcome. This has caused a lot of concern amongst chronically ill people. We explore the harm that this ideology may cause, and why it needs to be scrapped from any system that aims to support sick and disabled people.

Support outside of work

Current situation

People with chronic illness or disability generally have difficulties with areas outside of work, not just in the workplace (unless work is the source of the problem). The time and effort expended on these uses up energy and consequently reduces what is available for work. This is particularly an issue where a person's illness or disability causes fatigue; there may not be enough left over to enable a person to work consistently or well. At the moment, there is no provision in the UK for assisting sick or disabled people with routine household tasks such as shopping, cleaning, laundry or basic home maintenance. Neither the extra-costs benefit, PIP, nor social care cover these areas. Similarly, there is no system for assisting sick or disabled parents with caring for their able-bodied children; the child is healthy and therefore does not fall under the purview of children's social work, whilst the parent does not need help directly for him/herself and therefore does not come under adult social work. These factors need to be taken into account when considering what capacity is available for work.

As well as the lack of employment assistance and assistance at home, people with chronic illness or disability do not receive good-enough healthcare. The NHS is under immense strain, with an unprecedented inadequacy of funding coupled with bureaucratic demands that the NHS achieve more with less money, be more competitive (the 'procurement, patient choice and competition' regulations) and become more collaborative ('Sustainability and Transformation Plans' that recommend collaboration). Difficulty accessing GP appointments means more people have to turn to A&E for healthcare, whilst cuts to social care and benefits mean people's health is getting worse (Hastings, et al., 2015; Unison, 2016). Mental health wards have had occupancy rates as high as 138% (Crisp, 2013); waiting times are increasing (Murray, 2016; NHS England, 2017); and GP positions go unfilled (Pulse, 2016).

Social care is drastically underfunded, having lost £4.6 billion in England since 2010 and budgeted to lose another billion during this last financial year (Leonard Cheshire Disability, 2016). Spending has fallen to under 1% of GDP and there are 400 000 fewer people receiving care now than in 2009, despite an ageing and growing population (The Nuffield Trust, 2015; Leonard Cheshire Disability, 2016). Half of all disabled adults

who need social care get no care at all, whilst a third get less care than they need (Leonard Cheshire Disability, 2016). Baroness Pitkeathley (2012) said,

“The system is not fit for purpose and we spend inadequate amounts on care and support both publicly and privately. Social care funding has totally failed to keep pace with demographic change. Since 2004, while spending in the NHS has risen by £25 billion, spending on social care has risen by just £43 million...

“We cannot avoid recognising that the way in which local authorities have dealt with the fact that need has far outstretched funding has been to increase charges and rapidly to raise the threshold at which you can qualify for care. You get care only if your needs are seen as substantial or critical.”

Leonard Cheshire Disability (2016) wrote,

“There are some things none of us should have to experience in modern Britain... We believe that being left trapped in your home for days on end without vital support and human contact, or forced to stay in bed until 11am and go back to bed at 8pm are among them. Many disabled people tell us this is a daily reality for them.”

Since 2010, the NHS has been put under an “unprecedented slowdown in funding” which has brought it to “breaking point” (Robertson, 2016). Delayed discharge from hospital due to lack of social care has risen by 37% between 2015 and 2016 (Leonard Cheshire Disability, 2016). The target for A&E waiting times has not been met in three years. People with mental health conditions are receiving fewer appointments per year, whilst adult acute admission awards run at an average of 101%. Many have to go out of their area to get a bed, causing knock-on difficulties with arranging post-discharge care and an associated increase in suicide risk (McNicoll, 2015; McNicoll, 2016). Nurses are being replaced by lower-trained nurse associates, which is linked to a 21% increase in the likelihood of dying in hospital (Aiken, et al., 2016). Both the number of doctors per bed and bed occupancy rates are also linked to death rates (Jarman, 2016).

Other important services have also been reduced since 2010. Libraries, important for people with otherwise limited access to books, computers and the internet as well as for social interaction, have lost a quarter of their paid staff and reduced their opening hours (BBC News, 2016). The central government acknowledges that “local government funding is under pressure”, then casually says “Councils will need to take [funding pressure]... into account when restructuring budgets to meet strategic priorities” such as libraries (DCMS, 2016) without apparently recognising that both the funding pressure and the statutory duties are determined by central government. The only acknowledgement of library closures – 340 since 2008, with a similar number expected to close in the next five years (Poole, 2016) – is a section devoted to “Promoting positive messages about libraries in the media”, in which the government notes “It would be wrong to deny changes are occurring in the sector” whilst it bemoans the fact that the media is reporting the closures (DCMS, 2016).

The report by the Department for Culture, Media and Sport (2016) cited many benefits of libraries including “cultural and creative enrichment; increased reading and literacy; improved digital access and literacy; helping everyone achieve their full potential; healthier and happier lives; greater prosperity; and stronger, more resilient communities”. Labour’s shadow culture secretary cited the DCMS’s figures that a “five to one benefit to cost ratio is quoted as the return on investment in libraries”. Yet as Nick

Poole pointed out, “The government’s response to libraries being among our most used and trusted public services is to cut budgets and hollow out services” (Poole, 2016). The government cites a £4 million “Libraries: Opportunities for Everyone innovation fund” (DCMS, 2016), but does not mention the £25 million drop in funding between 2014/15 and 2015/16.

Public transport and the public environment continue to be disappointingly inaccessible for sick and disabled people (House of Lords, 2016). Deaf people report missing trains because they do not hear an audio announcement of a change in platform; blind people of not getting off at the correct bus stop because the driver forgot to notify them. Wheelchair users can be left stranded on trains when staff forget to bring the ramp, or on stations when lifts are out of order. Regulations to make all buses accessible to wheelchairs have been ignored, provisions for wheelchair users in taxis have not been brought into force since they were written twenty years ago, and bus staff have been given exemption from training on disability access.

The public environment is becoming, if anything, less accessible. Pedestrianised town centres leave disabled people unable to get close enough to shops or to ShopMobility centres to be able to use them. Benches and public toilets are being removed, turning town centres into ‘standing room only’. Shared spaces, where motor vehicles and pedestrians use the same space without distinction, render the chosen areas inaccessible to people with visual impairment.

Initial recommendation

In the previous report I recommended that assessments of capacity for work give consideration to the impact that lack of provision for needs outside of work has on the remaining capacity for work. A person should not be considered fit for work if work would impede their ability to carry out standard tasks of daily life and/or excessively restrict their ability to engage in the ‘rest and leisure’, including family, friendship and religion, which form part of our basic human rights.

Mental Health

The people with whom I spoke placed strong emphasis on the necessity of recognising that there are people who cannot work and are long-term unable to work. Employment support for this group is a misnomer. It is both irrelevant and harmful. What they needed, but did not get, was support in every other area of their life.

This was the same even for people with MH conditions who could or might reasonably be able to work. Support for work was not the only support they needed, and was incapable of being enough on its own. For many, it may not even be necessary: moving into work can be a natural progression following a sustained recovery from any illness. Again, what they needed – and did not get – was support in the rest of their lives.

Put simply, people with severe and enduring mental health conditions have been abandoned by this government to live without sufficient means; without access to effective and timely healthcare; without the support they need for their personal care, domestic tasks, family responsibilities and social participation; and without good-enough access to the general environment including retail, public transport and libraries.

There is a wealth of evidence to this effect, including in the previous reports in this series (Benstead & Nock, 2016; Benstead & Nock, 2016b). Inaccessible and unsuitable housing has a negative impact on health and well-being (Smith & Caddick,

2014), and poor quality housing is estimated to cost the NHS £2.5 billion/year from illnesses associated with damp, cold and mould (Friedman, 2010). Housing benefit cuts (Reeves, et al., 2016) and the transfer from Incapacity Benefit to Employment and Support Allowance (Barr, et al., 2015) have both been associated with increases in depression. Cuts in welfare are associated with increased inequality in health (Blakely, et al., 2008; Krieger, et al., 2008; Barr, et al., 2015).

People with severe and enduring mental illness receive neither the crisis support nor the ongoing support that they need in order to stabilise their lives, manage their health and have a decent quality of life. Additional harm is caused by the poor provision of public services such as public transport, open environments, libraries and day-centres. Further unnecessary stress and distress is caused by the social security system which conspicuously fails to provide them with any security or protection from want.

What people with MH conditions need first is good healthcare, and second good care in their daily lives. This includes adequate extra-cost benefits and/or social care to help them in their home, and the extension of extra-cost benefits to cover household tasks such as shopping, cleaning, laundry and basic maintenance. Outside of this, they need libraries and daycentres to be reopened, and public transport made more accessible including concessionary passes for people with mental illness.

All this support must be in place before any employment support can be offered, because without it the employment support is at best ineffective, and at worst has already driven people to suicide.

Physical Health

What the people in the physical health group needed were the very things the government has tried so hard to abolish over the last six years: a secure and livable income; good healthcare; an adequate standard of living; assistance with household, personal and social tasks; and access to the general environment. These are much the same requirements as healthy disabled people. The difference is that where healthy disabled people additionally need assistance to enable them to find and undertake paid work, sick people need instead the space to manage their illness. This is what the narrow coverage of the ESA Support Group has been unable to provide. Instead of giving people space, JSA and ESA WRAG have actively taken away from sick people the right and the freedom to manage their health, lives and wellbeing, and to choose what is best for themselves.

The most supportive thing the government could do, if it truly wanted sick people to be able to work, is to give them the space they need to recover, recognising as it does so that recovery is not inevitable and many sick people may never regain a capacity for work. This means that the government must equip the NHS with the funding necessary to meet the needs of chronically people; provide income that is secure and sufficient for an adequate standard of living; and provide cash or in-kind benefits to help sick people with the activities that their illness causes them difficulty with doing.

Brain Injury

The brain injury group reported that managing a brain injury was in itself a full-time job. They needed assistance at the level of 'micro-managing' in their daily lives, for such simple tasks as making a bed. They were unable to be independent because the level of support they needed in their daily lives was simply not available. Many reported being

dependent upon their parents, particularly their mothers, for daily support – even when their parents were well past retirement age.

The fatigue caused by their brain injury had significant impacts on their capacity for any work. Their lives were essentially a very restricted zero-sum game, in which to add in any additional activity – such as benefit assessments, conditionality requirements or work – meant that other important activity would then need to be done by a different person. In essence, it would mean an individual taking part in activity or work at the government's request, only for the government to then pay a separate person to do for the claimant what the claimant could no longer do for themselves.

If I'm going to work ten hours a week, I need someone helping at home. I can't use the same energy twice.

My mum gets on my case first thing in the morning and doesn't stop until last thing at night. This is how it will be for the rest of my life.

Learning disability

The learning disability group relied heavily upon the support provided by their local church for managing their daily lives. Day-centres had historically been helpful, but many had now been closed. They needed access to support outside of work, but rarely got it.

The group reported that they varied significantly from day-to-day in regards to their functional capacity. They needed the freedom in their lives to absorb life events and deal with problems or with fluctuations in their functional capacity as they came up.

Visual Impairment

For blind people to be able to work, it is necessary to provide support in all areas of life where it is needed. It is not possible to provide support only in the workplace or for work-search activities and assume that this will resolve any difficulties outside of the workplace. If significant time, energy or resources are being spent on necessary non-work activities then this necessarily limits what is available for work. Where support is needed for household, personal or social tasks these must be provided upfront. Work is not sustainable or good when basic support needs are not met.

Blind people therefore need first an adequate amount of cash and/or in-kind benefits to allow them to have safe, warm housing; an income that is both high enough and stable enough for an adequate standard of living; the ability to manage personal hygiene at times and in manners of their own choosing; and the ability to safely buy, store, prepare, eat and clear up after food. Without these, blind people will be hindered from work by the stress, cognitive pressure and illness caused by living in poverty in cold, damp housing; the risk of injury from poor household maintenance; and the risk of disease caused through difficulties with personal hygiene, toileting and storing and preparing food. Stress caused by difficulties with claiming benefits, the threat of income loss and the fatigue of compliance should be removed.

Some of these support needs are ostensibly met by Personal Independence Payment and social care. PIP, after extensive pressure from disability charities, does give people with visual or hearing impairment access to the higher payment level of its Daily Living component. However, this is far from the actual extra costs experienced by blind or deaf people. PIP considers only the impact on communication, and not on other problems such as seeing mould on food or hearing emergency alarms. It does not provide for an assistant to help with household tasks or to navigate the daily vagaries of life. Nor is there any support for disabled adults with caring responsibilities for other people. Social care is heavily restricted, rendering it essentially irrelevant to people who wish to work.

Hearing Impairment

Society causes difficulties for deaf people by using only auditory announcements, even though visual announcements are also possible. For example, buses that use auditory (or no) announcements of location make it more difficult for deaf people to know where they were. Telling a bus driver where a person wishes to go is impossible when that person does not speak English, but only BSL, whilst the driver only speaks English. When using trains and train stations, important announcements such as a change of platform or a train that is splitting in two are generally made by tannoy and not announced in a clear visual manner. In lifts, emergency alarms with connection to lift operators operate on an aural basis only, without cameras or a video relay that would allow visual communication.

Society does not routinely ensure the participation of deaf people. Simple activities such as visiting one's optician or bank are not possible when interpreters are not provided. Businesses rarely considered themselves to have a duty to make their service accessible, whilst those who made some attempts at access still refused to provide interpreters on the grounds that this was too expensive and therefore not a reasonable adjustment. Thus, an entire section of society is locked out from the rest of society, because those who can and should provide interpretation do not do so.

Deaf people are similarly excluded from social activities. Cinemas, for example, do not routinely provide sign language interpretation of their films. When subtitles are provided, these are in standard English, meaning the deaf person has to not only read but also interpret the subtitles whilst trying also to keep up with the film. Subtitled films tend to be at restricted times, such as Sunday mornings, meaning that deaf people do not have the choice of viewings that an able-bodied person has.

Society does not have to be like this. The deaf people to whom I spoke reported that the USA has a more appropriate approach to accessibility. In the USA, all cinemas provide subtitles or sign language interpretation, as do TV programmes and theatres. Businesses expect to provide an interpreter at the time and date requested by the deaf person, rather than telling the deaf person to come in at a time that suits the business. In Chilmark in Martha's Vineyard, an isolated community grew up where everyone learnt sign language and thus deaf people were fully included in that society. When Gay Pride held an event in Manchester (UK), it had an interpreter on stage throughout the entire event. It is, therefore, neither impracticable nor unreasonable to make society accessible.

The difficulties with benefits, restricted access to society and lack of support from government providers led to frustration and depression for deaf people. Although they tried to participate in society and, where possible, to work, this was frustrated by the government's negligence in not providing BSL interpreters when needed. The

constant battle to get accessible formats of benefit claims and conditionality requirements had a negative impact on wellbeing which only made getting work even harder. Long-term unemployment, or being unable to get work at a skilled or professional level, added to deaf people's depression.

Deaf people need the government to commit to providing the support they need to participate in society and in work. This means making sure that written English is comprehensible to people who have to translate it into BSL in their heads, and wherever possible to use video and relay links; for example, in shopping centres, at stations and on public transport, and in public venues. Deaf people must have access to the training opportunities, both in school and as adults, that will allow them to engage in work at their ability level, not just at entry level and in unskilled work. This must be available free, as of right, and in an accessible format. This will likely mean extending the remit of Access to Work to include BSL interpreters and other support measures for both training and voluntary work. The government must ensure, through legislation, enforcement and direct provision, that deaf people can attend businesses as both clients and employees and have access to a BSL interpreter as of right. These measures will ensure that deaf people have equal rights to hearing people in regards to education, training, work, the public environment and business.

Final recommendation

Sick and disabled people need support in a range of areas outside of work if they are to be or become able to work. These include household tasks, personal assistance, caring responsibilities and access to the public environment. For those people who have some capacity for work, these needs must be addressed first as otherwise an employment support intervention is unlikely to be successful. For people who do not have the capacity to work, even with support at home and in the public environment, that is no excuse for the State to neglect to provide what is needed for an adequate quality of life and participation in society.

We therefore recommend that:

- The government increase the remit of extra-cost benefits (Personal Independence Payment) to cover household tasks that have historically been excluded, such as laundry, cleaning, shopping, basic household maintenance, and additional utility or food bills.
- The government increase funding to social care so that it is available to all who need it, and provides all the support they need. Social care should be seen as a preventative service, with the goal of reducing demand on the NHS and reducing future social care spending by ensuring people do not escalate to severe or critical needs;
- Increase funding to the NHS for all services, and in particular for mental health (both crisis and long-term), GP, A&E, physiotherapy and occupational therapy;
- The government increase funding to local government so that day-centres and libraries can be reopened, public transport can include concessionary passes, and public environments be made more accessible;
- The government enforce and, if necessary, subsidise access requirements in public spaces;
- The government extend Access to Work to include funding for voluntary work and for training.

Support related to work

Current situation

The current policy regime in the UK focusses upon changing the beliefs, attitudes and behaviours of unemployed, sick or disabled people. It assumes that people are out of work because of poor cultural or individual attitudes to work. The Green Paper expressed concern about “the way individuals and groups of people think”, and spoke of needing to “develop our culture” so that sick and disabled people show “the right behaviours and attitudes” (DWP & DH, 2016). The political rhetoric has for many years centred on “long-term dependency” and “cultures of worklessness”, instead of talking about the provision of long-term (financial) support for as long as people need it. This language is “corrosive”, “de-motivating” and “counter-productive” (Dean, 2003). It encourages sick and disabled people to blame themselves, when the reality is that the open labour market is not suitable for them and has, in many cases, contributed to their illness.

The assumption that the main problem is one of attitudes and behaviours is not only unfounded but actively countered by the available evidence. This was known in 2010, when a DWP-commissioned report concluded that there are no significant differences in the overall work commitment between sick people who (improve and) return to work and those who don’t, leading the authors to “question the policy assumption behind ESA about the lack of work aspirations among recent IB claimants” (Kemp & Davidson, 2010). When talking to people out of work because of sickness, they typically want to work (Ali, et al., 2011; Kirsh, et al., 2012) and often will spontaneously mention work as something to be desired (Abberley, 1999). Many will have an intention to return to work, and even look for work, even in the face of ongoing health problems (Garthwaite, 2010; Kemp & Davidson, 2010). Indeed, the people who require the most sick leave can have the strongest views on the cultural unacceptability of taking sick leave (Tveito, et al., 2002); consequently, they may prolong their illness by not taking therapeutic time off work (Tveito, et al., 2002; Ashby & Mahdon, 2010; MacDonald, et al., 2012).

Work is not a cure for ill-health, and can in fact damage health. Previous estimates have suggested that 5-10% of employees may have their health harmed, rather than helped, by work (Warr, 1987; Tveito, et al., 2002; Waddell & Burton, 2006). A survey in Norway reported that 5-10% of power plant workers accounted for 82% of the sick leave (Tveito, et al., 2002), which may mean that a substantial minority of the working population consistently struggles to manage work and health together. In the UK, there has been a significant ‘hollowing out’ of the workforce with an increase in low-skilled, low-autonomy and high-pressure jobs (Finegold & Soskice, 1988; Casebourne & Coleman, 2012); such ‘high strain’ jobs are both detrimental to health and more difficult for people with chronic illness to perform (Baumberg, 2011). The influential Marmot report concluded that “toxic” combinations of working conditions are “frequent” in the UK (Marmot, 2010). In this context, it ceases to be surprising that around 6-7%¹ of the working-age population could be assessed as too sick or disabled to work at any one time.

¹ Using an average of 2.5 million people on sickness benefits since 1995, with an estimated working-age population of 36 million in the 1990s and 42 million in the 2010s.
<https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/articles/overviewoftheukpopulation/february2016>

The problem is not that chronically sick people generally don't desire to work, but that they aren't well enough to work. Most of those who enter work do so because their health improved (Kemp & Davidson, 2010; Corden & Nice, 2006c), but health improvements aren't always sustained, especially if work is not built up gradually (Corden & Nice, 2006a; Corden & Nice, 2006b). In the Netherlands, employees on sick leave aren't expected to discuss ways to resume work until their health has begun to improve (Meershoek, 2012). Yet the Green Paper (DWP & DH, 2016) gives no indication of recognising that many people are long-term too sick to work, or too sick for it to be reasonable to expect them to work. Instead, it focusses on what may be termed 'public health' conditions, and assumes that a combination of low-level Cognitive Behavioural Therapy, some physiotherapy and a return to work will cure people (Richardson & Benstead, 2017).

The DWP already has evidence on what doesn't work. A number of programmes including the ONE Advisory Service, New Deal for Disabled People, Pathways to Work, Condition Management Programme and the Work Programme have demonstrated, both in their low success and in DWP analysis of their performance, that low-level interventions don't work (Clayton, et al., 2011). High caseloads mean staff can't give the time that is needed to the people they are supposed to be serving (Nevile & Lohmann, 2011). Inadequately trained staff aren't able to give advice that is appropriate to an individual's condition (Corden & Nice, 2006b; Baumberg-Geiger, in press), nor refer to appropriate support services (Clayton, et al., 2011; Baumberg-Geiger, in press). Sanctions are detrimental to effective employment support (Clayton, et al., 2011; Nevile & Lohmann, 2011; Meershoek, 2012). What does work is low caseloads, long-term sustained and staged support, and knowledgeable, experienced staff (Clayton, et al., 2011) – coupled with improvements in health (Corden & Nice, 2006b). Sadly, none of these are met by the JobCentre, the Work Programme or the government's Green Paper recommendations.

Assistance with application forms, CVs or interviews for specific jobs is not currently provided. ESA recipients with low skills, or with unusable skills, are not given the opportunity to train for industry-recognised qualifications. Recipients needing adjustments to an otherwise standard job do not receive an assessment of their needs, and cannot compete unassisted with people who can carry out all of a job's requirements without adjustment. The government does not pay for job brokers who could liaise with employers to create or modify jobs for chronically sick or disabled people, and nor does it help employers with the costs of employing a person with chronic illness or disability – Access to Work is notoriously slow. At no point in a person's sick leave does the government actively consider what other assistance is necessary, such as for household tasks, personal care or caring responsibilities.

The sick and disabled people who responded to our survey indicated that, for those who were well enough to do some work, a key factor was the willingness or not of employers to employ them and to provide the necessary adjustments. In previous research with employers, the DWP has established that employers would appreciate having more detailed, specialised and easily accessible support for employing sick or disabled staff. Employers wanted the JobCentre to act more like a recruitment agency, with Account Managers who have "specialist knowledge of business and staffing issues in the relevant business sector" in each JobCentre (Bunt, et al., 2001). They also wanted to have specialist Personal Advisers who could support both the sick or disabled person and the employer, during the recruitment process and for up to six months afterwards (Bunt, et al., 2001; Davidson, 2011). The provision of Account Managers and Personal

Advisers would improve the purpose and performance of the JobCentre, making it more like a recruitment or employment agency and thus better able to serve claimants. Employers felt that this would improve the matching of jobs to sick or disabled people.

More recently, Gabbay et al. (2011) reported that there is “clear scientific evidence” for a case worker who can carry out an early assessment for the reasons for sickness absence. This clearly requires someone at a higher level than a nurse or physiotherapist, and even a higher level than a doctor with a few weeks’ ‘disability training’. It needs someone who can not only look at what health factors are causing a person to have difficulties at work, but also the extent to which the job itself is causing, contributing or prolonging those health issues, and what wider problems might need resolving. This caseworker must be able to coordinate interventions to promote returns to work for people on sick leave from a job, including liaising with both healthcare professionals and employers. They must therefore have a high degree of expertise; a typical profession that might be able to provide such expertise is Occupational Therapy. This profession uniquely trains its members to assess both functional ability and support needs across a range of activities.

Australia

The payment-by-results method chosen by the 2010 government for its Work Programme has been known for some time to be unable to meet the needs of people who can’t work or who struggle to work. It is too easy for companies to ‘cream’ off those who need little or no support to return to work, whilst ‘parking’ those with expensive needs (Work and Pensions Committee, 2013). Australia has used a similar system since 1998, and after ten years of use there was widespread dissatisfaction with its poor performance and approach (Nevile & Lohmann, 2011). There was insufficient up-front funding to cover the costs of people who would need long-term, expensive support. The ‘results’ which were paid for were too far away, and unachievable for many. More importantly, the payment-by-results method meant chiefly that the risks to the government were minimised, rather than the risks to individuals, yet in an industry supposed to serve citizens it should be the other way around. The individuals were unable to choose where they went for support, because they were restricted to the government-selected provider regardless of the performance of that provider at that time.

Aside from the inappropriate payment method, Australia’s experience has other things to say to the UK. A key issue was the experience – or otherwise – of the support staff. It was found that “a major difficulty was the breadth of experience required to deal competently with the broad range of disabilities presented.” Staff needed to be specialised in the condition of the person they are supposed to be assisting; the comments from our focus group participants confirm that it was specialist charities that were the most helpful, whilst JobCentre and Work Programme staff provided no helpful support. This specialisation must include an understanding of and expertise in the (main) condition experienced by the sick or disabled person. There is no value in non-specialised support staff, such as the Work Coaches proposed by the DWP and DH in their Green Paper.

Australia found that ‘work’ was a very long-term goal for many, if it was appropriate as a goal at all. This not only made it difficult financially for the private providers – who had to invest substantial resources over a long period of time before any return could be expected – it also placed inappropriate and unhelpful pressure on claimants. This was despite the fact that these claimants had been assessed as likely to

be capable of 15+ hours/week of work in the open labour market within 24 months. Claimants felt stressed and put under pressure to take work or engage in activity that was beyond their capability. The employment support staff in Australia found that chronically sick people, particularly those with mental health conditions, tended not to follow 'linear' paths to recovery; rather, they would have some improvement followed by relapse. There was too much emphasis on work when what claimants needed was assistance with life issues and (re-)training alongside assistance with healthcare and health management. This was detrimental to the likelihood of employment, as the focus on jobs means that other methods such as improving capacity for activity generally, and thereby for jobs, were undermined.

Many staff who worked for private companies, on behalf of the Australian government, left the private sector to work in the third sector. When working for charities, the staff reported that they were better able to help claimants because they were given the opportunity to assist in the claimant's overall life, rather than a narrow – and ultimately unsuccessful – focus on jobs. It was important that they had a low caseload, no more than 20 per support worker, and were able to make appropriate recommendations to their claimants rather than inappropriate requirements. Consistency and continuity were important to ensure that claimants received effective support.

Initial recommendation

For sick and disabled people who currently have capacity for work, the government should provide up-front the support that is needed for them to be able to work. This should be done in a timely manner so that work-place support is available at the time that a job is supposed to start. Support is not restricted to putting in place the necessary adaptations and assistance at work; it also includes pre-work support. This pre-work support includes extending the remit of Access to Work to include volunteering and training, thus allowing sick and disabled people to 'trial' work in a more flexible and sympathetic environment. It also includes providing job brokers as a matter of course, to assist sick and disabled people to gain employment, in recognition that employers do not typically know what they and the government can do to help sick and disabled people, and therefore do not know which sick or disabled people they could employ in what role.

Mental Health

The MH focus group reported they had never received any beneficial employment support from the JobCentre or from Work Programme Providers. Their experience was that the advisers they saw did not have the knowledge or experience to understand the needs of people with MH conditions, and therefore were unable either to provide the necessary support or to make appropriate conditionality requirements. Indeed, as what this group needed was adequate healthcare and community support, there was no appropriate role for the JobCentre.

Return to work isn't support, it's a threat to wellbeing.

Back to work therapy is no therapy at all.

The group was clear that they could not and would not support workfare. Whether it was called work experience or work placements, the requirement to work without paid recognition from either the DWP or the employer was seen as solely negative. If a job was available, employers should pay an employee to do that work. Anything else was 'profiteering off the backs of disabled people', benefiting the employer whilst doing nothing for the mentally ill person. The time this took up cost them in other areas of their lives, and caused pressure and distress that worsened their mental health.

The group recognised that a significant barrier to their employment was the change in the open labour market over recent decades. The UK has seen significant deregulation since the 1980s, allowing employers to withdraw from supporting their own employees, particularly at the lower end of the job market. The increase in pressure in the workplace has been recognised in the academic literature as a particular problem in the UK, and as one that contributes significantly to mental illness and reduced capacity for work. The group reported that their experience was that they were not able to keep up with the speed, pressure and workload expected of people; it simply was not compatible with their illnesses. They felt that in focussing on people who were out of employment, including the chronically sick, the government was avoiding its responsibility to provide decent jobs and to mitigate the consequences of job deregulation.

They pointed out that the country does not have enough medical professionals specialised in mental health, whether doctors, nurses or occupational therapists, to support people with MH conditions to work. This was the case even when considering only those people whose conditions were sufficiently mild for work to be possible, either immediately or as a two-year goal. Without the adequate mental health care, any employment measures – even if there were enough employment support staff – was doomed to not only fail, but to make worse the health, lives and closeness to work of the people concerned.

The mental health group was very opposed to the Individual Placement and Support (IPS) model of employment support. This was largely because they felt that the emphasis on work was inappropriate when they had yet to receive the support they needed for their health and personal lives. Employment support was unlikely to be successful until the health and societal barriers were resolved. For people in the early stages of a mental illness, employment support should not be provided until adequate healthcare and support outside of work has been put in place.

IPS studies on people with severe mental illness have typically drawn their participants from people receiving Community Mental Health Team (CMHT) or Early Intervention in Psychosis (EIP) services. Sadly, the severity of underfunding to mental health, particularly for anything beyond the Improving Access to Psychological Therapies level, meant that many of the original Ekklesia survey respondents reported that they were not receiving such services, and none of the mental health focus group participants had CMHT or EIP support. This is a problem, because close working with mental health services is a key factor in successful employment support programmes for people with mental illness (Drake & Bond, 2008). The combination of Community Mental Health Teams with "dedicated vocational specialists" is vital (Schneider, et al., 2009; Heffernan & Pilkington, 2011). It is not enough to simply train Community Mental Health Teams in the practice of IPS, and expect that this will do (O'Brien, et al., 2003).

This is in stark contrast with the government's expectation that non-medical, non-specialist 'Work Coaches' can, with the assistance of 500 'Disability Employment Advisers' and 200 'Community Partners' for 2.5 million sick and disabled people, get significant numbers of sick and disabled people into work. If the government will not

dramatically increase funding to both CMHTs and vocational mental health specialists, it will achieve nothing beneficial and instead will likely cause significant harm to people with severe and enduring mental health conditions. There is nothing good about forcing people into a substandard service.

The evidence base of IPS continues to be limited. The reports tend to focus on positive outcomes, but don't comment on the impact of mandation, excessive activity requirements or threat on people who do not receive adequate mental health support. People do drop out of IPS programmes, and by definition the reasons why are usually unknown. A recent study felt it necessary to include training and education in its measures of success, because job take-up alone was too low to represent a success (Boycott, et al., 2015). When employment support is given, it is necessary to give serious consideration to the individual's preferences and interests. The IPS model is about placing people in appropriate jobs, not in any job at any cost. The success of IPS, as with all supply-side measures, is limited when job availability is low.

The group I spoke with were too ill to work, as their experience of their daily lives and the benefits system showed them every day. The mental distress they experienced was distressing and exhausting, and they did not have the capacity to add work on top, even if it were good work. What they needed was a stable life without the threat of losing their benefit. Employment support measures were simply not relevant, let alone appropriate, for them.

The group agreed that employment support could be helpful in the early stages of illness. However, it was stressed that this was only in the context of there being adequate healthcare and home care provided first; that it was at the desire of the mentally ill person; and that support meant the government putting in place, and enforcing, such measures as requiring employers to allow altered duties, reduced hours and phased returns to work – and did not mean telling mentally ill people about timekeeping, motivation and self-discipline. In everything the group discussed, it was in the context of making improved or stabilised health and wellbeing the prime goal, to which work was always completely subordinate.

Physical Health

The physical health group were largely too unwell for discussions of work-related support to be relevant to them. There is a particular need when supporting people with chronic illness that the expected 'supported' activity, however apparently suitable, does not exhaust the individual's capacity for activity. For many, the most appropriate support is the access to rest and freedom from want which will allow people to maximise their health, capacity and well-being within the constraints of a chronic illness. This means providing not just an adequate income-replacement benefit, but also an adequate extra-costs benefit and good quality healthcare.

Where employment support is available, this group considered that it should be on a voluntary basis, thus ensuring that people who are too ill are not placed under compulsion to take part, or at risk of such compulsion. The group reported that people who are well enough to work typically want to work and will take advantage of any decent employment support that is available. Such support should include job brokerage and the opportunity for re-training where a chronic illness means that a new line of work would be more suitable.

One of the biggest problems with the system is the suspicion and lack of trust which underpins it... The vast majority of ill people are chomping at the bit to recover and return to paid employment, will know when they're ready and will inform the DWP without prompting.

Brain Injury

The group spoke positively about the staff at the charity they attended for their support group, and felt that it was people like the charity staff who should carry out any assessment and provision of support. The charity staff had been very helpful in teaching strategies for managing memory and cognitive problems, and were supporting a couple of the participants to do a small number of hours' of work each week. They recognised, however, that most people with brain injury struggled greatly in their daily lives, and needed considerable support to do even a few hours' of work in a week.

Access to Work was considered to be "neither use nor ornament". It made no provision for what was actually needed. The capacity for work was heavily curtailed by the sheer effort required to get through daily life, so even those who did do some work did no more than ten hours in a week. Any more than that was not sustainable. For those ten hours to be doable, it was necessary to work in a quiet environment without the noise and distraction of being in a shared working environment. Job tasks had to be ones that required identical procedures every time, and a set structure, combined with the provision of clear lists and checklists. Job tasks that required even small variations or which did not have a clear, written procedure were essentially impossible for this group. Consequently, their capacity for work was small and their employability even lower. Appropriate support to work for this group therefore means having a job broker who could create such a job within a business, plus a support worker to help with the job tasks. In practice, it was very unlikely that such jobs could be created and sustained. For many, therefore, the most realistic option for achieving the 'latent benefits' of work was to continue to attend their support group, and for the government to provide the financial benefits necessary for independence.

The group concluded that there needs to be an increase in the existence and availability of charities that support people with brain injury. The group members received significant benefit from the group they attended, from social, emotional and practical support. However, the charity staff reported that they did not know of any other similar charity in the country, meaning that the majority of people with brain injury do not get the support they need. This included assistance with claiming benefits. The government should increase funding for organisations that support people with brain injury.

Learning disability

The group spoke favourably of Remploy, day-centres and volunteering opportunities. They benefited from environments where they were not vulnerable to abuse from colleagues or managers, and where they could work at their own pace without pressure. One person suggested that local councils could employ learning disabled people in activities like litter picking, where they did not have to interact with clients or colleagues apart from other learning disabled people. This would provide them both with work and social participation within their peer group.

JobCentres and Work Programme providers had not proved helpful, and the limited depth of support on offer from these organisations was not relevant to the needs of this group. In essence what they needed and wanted was supported employment for those who could do some work and who wanted to work, and access to day-centres, support groups and volunteering opportunities.

Visual Impairment

As with other focus groups, the blind people and caseworkers with whom I spoke considered that it was necessary to put in support for life outside of work before looking at support in the workplace. This is discussed elsewhere. In terms of support in the workplace, this was considered at the simplest to mean transport to work and assistive technology in the workplace. However, this is unlikely to be enough. Visually impaired people need support to find and apply for work, because standard forms of work-search that rely upon visual adverts and application forms, and the ability to communicate well in standard English, are more difficult. Advertised jobs typically involve some tasks outside of a blind person's capacity, and employers are unlikely to modify an advertised job without a convincing reason to do so. For this reason, job brokers are often necessary and important to encourage and assist employers to create jobs suitable for disabled people. As well as assistive technology, disabled people may need continual access to support workers and physical adaptations to the workplace.

Some blind people will experience additional difficulties and therefore need additional support. These might be other physical or mental health problems, whether distinct from or contributed to by their visual impairment; additional responsibilities at home; or other work-related barriers such as unfamiliarity with computers or a low level of education. The people to whom I spoke also raised the issue of lower working speed; although not every blind person thought they worked at a slower speed than sighted people, some did report that they had been unable to keep pace when in work.

Bottom line is no amount of reasonable adjustments or financial incentives to bosses will ever amount to my being able to work...I am just less productive in a world where money matters.

The people with whom I spoke were concerned that blind people should not be shoved onto basic jobs due to lack of support for something more advanced. Blind people should have the same opportunities as everyone else to work in jobs that match their abilities and interests.

It sounds like working on a computer is the modern version of the old telephone switch boards which used to be where blind people were parked.

The blind people and case workers with whom I spoke had not experienced any help from the JobCentre. In fact, they reported that the JobCentre was actively detrimental because staff would require blind people to undertake activities that were physically impossible without sight. JobCentre staff were experienced as being insensitive and unable to adapt their working practices to meet the needs and capabilities of blind people.

Hearing Impairment

The deaf focus group reported that they are rarely able to engage in the support being provided at JobCentres or Work Programme providers, because it is not in British Sign Language (BSL). The ostensible adjustments, of being seated near the front and being given written versions of spoken text, are not any use to people who cannot hear and do not speak English. People who have been deaf from an early age are not fluent in English and have no opportunity to be; written English is therefore as inaccessible to them as spoken English. The experience of deaf people was that JobCentre staff and Work Programme Providers did nothing to help them, bar the occasional adviser who told a deaf person about the existence of a regional support centre. No training or other beneficial courses were offered, let alone made accessible.

Access to Work was considered essentially useless. The system was not fast enough to provide a BSL interpreter for a deaf job candidate at an interview. At the same time, Access to Work itself expected fast responses to the information it wanted, and would close the claim if a response was not received within a small number of days. If a deaf person did get a job, the level of detail asked for by Access to Work and its style of micromanagement rendered the process unusable. Detail such as exactly how much time would be spent on every individual aspect of a job was neither relevant nor answerable. Deaf people reported that they felt as though Access to Work was trying to catch them out and prove that they did not need support, rather than trying to understand what support was needed and the best way to provide it. They also found that Access to Work was more concerned about price than about what worked, and consequently would provide cheaper versions of assistive technology that were not of a high enough quality to be helpful.

There was no support available for training, work experience or voluntary work. In theory, BSL interpreters would be provided for job interviews and for in-work training, but the former took too long to organise and the latter was little more than a pipe dream for people who never got the support they needed to access work in the first place. Access to Work does not cover training for industry-recognised qualifications, even though these would create access to jobs. Nor does it cover voluntary work or work experience, even though these would help by giving deaf people the space to learn a new job and demonstrate to employers that a deaf person can work successfully. Indeed, deaf people felt that they were more productive in an office than a hearing person who is more easily distracted by chatter; deaf people may also be safer at work in noisy environments because they are used to being visually aware and are therefore less reliant upon being able to hear alarms.

The deaf people whom I met reported that they had been helped by their local deaf charity. The charity had delivered programmes that taught them techniques for engaging with hearing people and managing their deafness in a predominantly hearing country. The charity also assisted them with benefit claims and job applications, in particular in regards to translating English into BSL and vice versa. They also provided assistance with accessing training, apprenticeships and voluntary work. The deaf people reported that the support from the charity boosted their confidence in engaging with hearing society and in applying for jobs. However, the charity was only able to serve local people, and the majority of deaf people did not have access to a similar charity in their area.

Other

A common theme in Ekklesia's survey was that people with chronic illness who can do some work need the flexibility to arrange that work around their lives. Most importantly, they need the freedom to refuse work when they are not well enough to do it. But they also need a stable income, and this means they need freedom from financial pressure to work when it is detrimental to their health. They therefore need fully flexible hours – i.e., being in control of when they work, how much they work, what work tasks they do and where they work – and paid disability leave. They need employers who will change businesses practices to suit chronically ill employees, not employers who will dismiss chronically ill employees on the grounds of incapacity.

For many, the most suitable option was a long-term benefit, which they could top-up by doing small hours of work as and when they were able to. However, in reality many were unlikely to find such work in the labour market, because it is not compatible with employers' needs. Volunteering opportunities could be suitable, if Access to Work increased its remit to support people in voluntary work.

Final recommendation

What is needed is a change in approach that recognises that the problems holding sick and disabled people back from work are not ones of poor motivation, confidence or time-keeping. It is for many the simple fact of their ill-health or disability, whilst for others it is the pressure of the modern workplace combined with their illness or disability that means they cannot sustain work. People who are sick need time and space to manage their health and, if possible, reach job-readiness (Dean, 2003); the State must recognise that not everyone has a curable condition or one that can be managed sufficiently well for work to be or become viable (OECD, 2003). Sick or disabled people who have some capacity for work need practical support to be put in place - such as assistive technology, BSL interpreters, transport and paid disability leave - and job brokers to liaise with employers to find or create jobs that are suitable for them.

Fundamentally, the factors that hold sick and disabled people back from work are not factors that are due to the individual or that can be resolved by the individual. They are factors that are the responsibility of the government, and whose lack of availability is the fault of the government. It is the government that carries responsibility for ensuring that the society it governs contains jobs that are appropriate for sick and disabled people, and for ensuring that employers are in a position that makes it viable for them to employ sick or disabled people. It is, therefore, the government that needs to change its behaviour.

The DWP has had available to it recommendations on how to give employment support to those sick and disabled people who do have some capacity for work for many years. For example, in 2003 Dean was recommending that support workers for sick and disabled people be "street-wise, highly knowledgeable about the full range of services, entitlements and vagaries of the local job market" (Dean, 2003). This extent of knowledge is what our survey respondents and focus groups were asking for (for those who could do some work). It is in stark contrast not only with what is currently provided, but even more so with what the government plans to provide: non-specialised work coaches, assisted by a small number of disability specialists (for knowledge of disability) and an even smaller number – fewer than one for every three constituencies – of community partners, who will allegedly have knowledge of their local job market (DWP & DH, 2016).

Dean also recommended that employment support should be “independently based in an adequately funded voluntary sector”. The voluntary sector has considerable expertise in assisting people with different health conditions, albeit that some of this has been lost due to funding cuts over the last six years. By allowing choice, people have the freedom to go to the more successful organisations for their condition, which in time naturally improves the outcomes and quality of the available support. The DWP should fund the types of support that sick and disabled want, both by paying organisations upfront for the sick and disabled people who come to them for support, and by paying for support measures such as healthcare, retraining, and assistive technology, and access measures for volunteering and training as well as in the workplace.

Supporting people into work takes time. A study on the Individual Placement and Support model, for example, took two years to get 22% of its participants into work (Heslin, et al., 2011). A major flaw of the Work Programme was the way people’s benefit categorisation could change during the two years, from no conditions through to being required to apply for jobs. Sick and disabled people would be better served by knowing that they will not lose their sickness benefit whilst they engage in employment support, thus allowing them a stability of income that protects them from stress and financial strain.

For those sick or disabled people who can do some work, it is necessary that suitable jobs be available. The UK has a low skill economy (Finegold & Soskice, 1988; Casebourne & Coleman, 2012) which, through the typical ‘high strain’ of such jobs, is unsuitable for sick and disabled people (Baumberg, 2011), as our focus groups pointed out. The ‘skilled trades’ that disabled people used to do have been lost, and unless the government sets a deliberate policy – perhaps through supported employment – to introduce such jobs to the economy, it may find it impossible to provide employment for this group of people.

Much could also be done to improve the quality of entry-level, unskilled and low-skilled jobs, especially in terms of working conditions and pay, but unless it is also possible to reduce the expected speed of work then sick and disabled people may still not be able to gain employment in these jobs. Improving the quality of jobs at the bottom of the labour market would require regulation from the government, something which it has not appeared interested in doing. However, such a measure could not only open up more opportunities for people with (less severe) chronic illness or disability, it could also reduce the development of chronic illness in the first place. Work is a key part of most people’s lives, and a healthy workplace is vital to a healthy life.

Finally, and most importantly, it is vital that the government realise and recognise that a substantial proportion of the UK working-age population, including but not limited to the majority of people on ESA, are too sick to work and are unlikely to become able to work. Severe, non-curable illness is a reality and is not limited to progressive and terminal health conditions. The people in the mental health, physical illness and brain injury focus groups were emphatic that they, and the majority of people like them on ESA, were too ill to work and so severely and enduringly ill that work was not a realistic prospect in the future. They received no value from ‘employment support’ and were at substantial risk of harm from being required to engage in activity that disrupted their carefully managed daily lives. If anything were going to bring these people closer to work, it would be the freedom and time to manage their health and the adequate provision of health, social and personal care. As far as the social security system goes, this means an adequate level of benefit without reassessment or conditions; but whilst this is necessary, it is not enough for the State to stop there – it

must also invest in health, social and personal care so that chronically ill people are not left without support for a better quality of life.

We therefore recommend the following:

- The government shoulders its responsibility to provide enough jobs for the working-age population who can and want to work; to regulate these jobs to ensure that they are not detrimental to health; and to ensure that there are jobs that are designed for chronically ill or disabled people, in particular by expanding skilled trades and manufacturing, and providing supported employment for those who need such an environment;
- The government provide financial support to employers from all sectors and of all sizes, to cover the costs of taking on a chronically sick or disabled employee. These costs include subsidising employees who are less productive; subsidising employees who need more time off due to their illness or disability; contributing to the cost of managing workflow and staff rotas; and contributing to the cost of workplace adaptations, assistive technology, BSL interpreters and other such support;
- The government provide job brokers in all JobCentres who can build working relationships with local employers, directing them to the support that the government offers for employing chronically sick or disabled people and working with employers to create jobs suitable for chronically sick or disabled people;
- The government provide chronically sick and disabled people with adequate financial support for as long as they need it.

Healthcare and work

Is work a health outcome?

The DWP's and Department of Health's Green Paper wants to make work a health outcome. This is not something that was brought up in Ekklesia's original survey because it was not, at that time, an extant risk. However it did come up in the focus groups because of the recent Green Paper and DWP focus on links between health and work. The mental health group in particular was deeply worried about the inappropriateness of such a link being made for people who are too sick to work and whose health is made worse by work. The physical health and brain injury groups raised similar concerns and counter-arguments to the mental health groups.

The positive association between work and good health does not mean that work cures ill-health. No reasonable person considers that to be an appropriate interpretation of the link between health and work. Good health is requisite for sustaining work. Some people are too ill to be able to work or sustain work, whilst others are well enough to work and sustain work. Thus, there is a broad correlation between health and work. On the other hand, some people whose health is damaged by work are in work out of financial necessity, whilst other people who are healthy are out of work because of personal choice, caring responsibilities or old age. Thus the association between health and work is not exact.

Setting work as a health outcome is a fundamentally incorrect approach that misdiagnoses the cause of the problem and therefore leads to an inappropriate and actively harmful solution. The fact that sick people are less likely to be in work, and that

people out of work are more likely to be sick, does not mean that unemployment is the sole and direct cause of illness or that work directly and universally prevents or cures illness. If work directly prevented illness, no employed person would ever get sick. If unemployment necessarily caused illness, then every unemployed person – whether retired, raising children or studying – would be sick. But illness and disease exist irrespective of work. Work cannot cure Crohn's any more than it prevents cancer.

Students, volunteers, stay-at-home parents and pensioners are all groups who can manage to remain perfectly healthy despite not being in paid work; indeed, pensioners report improved health after leaving work (Ding, et al., 2016). Therefore, work is not necessary for maintaining good health. People in high-pressure, low autonomy, insecure, low paid jobs can all become ill as a consequence of being in work (Marmot, 2010; Baumberg, 2011). Therefore, work is not sufficient for maintaining good health.

What is important here is not the fact that there is an association between work and health, but the question of what are the mediating factors. What is it about work and about health that means that, very broadly speaking, people in work are healthier than people not in work? This is the question the government should be asking. The answer will tell us what is the right help to give people who are unemployed and healthy, to people who are sick but in work, and to people who are both unemployed and sick.

Fortunately, this is a question to which we have the answer. Employment is considered to hold both 'latent' and 'manifest' benefits. The latent benefits are time structure, social contact, collective purpose, activity and identity/status (Jahoda, 1981); the manifest benefit is freedom from financial strain (Fryer, 1986). Each of these benefits can be obtained through a variety of means, such as voluntary work, caring duties, inherited wealth or a partner's income. Paid employment, unlike most other activities, has the potential to provide all six benefits, although it is generally the case that people seek social benefits outside of work as well. However, paid employment is not guaranteed to provide all six benefits purely by being paid employment. Nor does unemployment invariably mean that a person is locked out of all six. There is no employed/unemployed dichotomy; people can have good unemployment and bad employment.

It is commonly assumed that unemployment is bad for health, to the extent that it is treated – at least by the DWP - as invariably causing mental health problems. However, there is significant variation in mental health across the general population, and employment status adds only a small effect to the overall differences between individuals (Fryer & Payne, 1986). Some people, particularly those who are higher-educated or who have higher levels of self-esteem or neuroticism, are essentially protected against the harmful effects of unemployment on mental health (Schaufelt, 1992), although this may be only temporary or only available to a small minority (Evans & Haworth, 1991). Conversely, "unemployed people who are in financial trouble, have been highly committed to their jobs, who hold strong negative attitudes towards non-work and being unemployed, who are socially isolated, and who experience a weak sense of self-esteem are particularly vulnerable to negative consequences of unemployment" (Schaufelt, 1992).

Employment is not a universal protector against mental illness. An individual's personality is a significant mediator of the impact of in-work stress on their mental health (Ivancevich, et al., 1985; Armstrong & Dudgeon, 1988). In Britain, at least in the past, 10-15% of employed people have been considered to be in need of 'immediate professional help' for mental or physical illness at any one time (Fletcher & Payne, 1980),

whilst 10-15% show improvements in mental health after losing their job (Schaufelt, 1992) – so it is not the case that unemployment is always bad for people’s mental health, or that being in employment always maintains good health. Despite the government’s, and in particular the DWP’s, attempt to simplify this relationship to an essentially dichotomous one, its real complexity has been known for years: “simplistic identifications of work as ‘good’ and unemployment as ‘bad’ are manifestly inadequate” (Ezzy, 1993).

Looking at what harms mental health whilst unemployed – low income, low self-esteem, strong disapproval of unemployment, social isolation, lack of fulfilling activity – it would seem as though the State has, over many years, created a so-called ‘social security’ system that deliberately targets these areas to make unemployed people worse off. The State has successively reduced income whilst creating a culture that derides unemployed people as ‘scroungers’ and ‘lazy’, and it forces unemployed people to engage in meaningless activity – whether workfare or excessive job-search – without allowing or assisting unemployed people to engage in meaningful activity that could improve their access to paid work. Unemployed people absorb the stigmatising message that the State thus provides for them, which corrodes their self-esteem and sense of worth (Dean, 2003), even whilst they are kept in financial distress. A worse system could hardly have been devised had the governing politicians set out to design a system that harms the mental health and employment chances of unemployed people.

But it is not impossible to protect unemployed people from want and distress. Unemployed people who have access to the latent benefits of employment - structure (Jackson, 1999; Martella & Maass, 2000; Waters & Moore, 2001), social contact (Warr, 1987), collective purpose (Warr, 1987; Haworth & Paterson, 1995; Martella & Maass, 2000), activity (Haworth & Ducker, 1991; Evans & Haworth, 1991; Goodman, et al., 2016) and identity or status (Creed & Macintyre, 2001) - have better mental health than unemployed people who do not have access to these benefits. The manifest benefit, income, also has an impact on mental health, due to the stress and strain of living in poverty (Rowley & Feather, 1987; Feather, 1990) and the consequent reduction in control and ability to achieve one’s goals (Fryer, 1986).

Work can actively cause harm, as has been well established both generically (Waddell & Burton, 2006; Marmot, 2010; Shildrick, et al., 2012) and specifically (EHRC, 2010; Cadwalladr, 2013; BSISC, 2016). Indeed, in contrast to the current mantra that ‘work is good for you’, the researchers Fletcher and Payne wrote that “It has been thought for many years that a person’s job or work can adversely affect his or her health or well-being” (1984). The ‘higher up’ an employee is, the better access they have to the latent and manifest benefits, and the better wellbeing; people in unskilled, insecure and low-wage jobs have significantly reduced access to the latent and manifest benefits (Selenko, et al., 2011). Low quality jobs and bad working conditions can counteract the benefits of employment, especially amongst less qualified people (Feather & O'Brien, 1986). High demand, low discretion jobs are the worst (Karasek, 1979; Baumberg, 2011). Unskilled work results in psychological strain from boredom, caused by the underutilisation of people’s abilities in simplified work (Caplan, et al., 1975). Therefore, ‘work’ is not the appropriate goal; it is the six benefits that should be the goal of government policy, and whilst work can be one way to provide them, and an efficient way, work cannot be assumed to be the best way without regulating and monitoring the work environment to ensure that it is in fact providing all six latent benefits.

The DWP’s own seminal paper on work and health suggested that as much as 5-10% of the employed population might see an *improvement* in their health if they left

work (Waddell & Burton, 2006). Fraser (1947) reported that 10% of the working population has 'definite and disabling' neurosis. Tinnings (1975) considered that 5% of the working population showed signs of strain so severe that they required the continual assistance of very skilled psychiatrists or counsellors. Sir Michael Marmot's renowned work on health inequalities referred to "toxic" combinations of damaging work conditions as "frequent" in the labour market (Marmot, 2010). This leaves aside the people with chronic illness who are unable to work, regardless of the nature of the job.

What we see, therefore, is that the link between health and work is complex. Bad work would not be appropriate as an outcome, because of its detrimental effect on health and wellbeing. Where someone has returned to work, this might be to a bad job or because of financial pressure, with the result that work then makes their health worse. Using 'work' as the outcome would count these people as recovered when in fact they had not, and when their health was suffering as a consequence of work.

Recovery that sees a person able to work full-time could be a health outcome, not because of the ability to work per se but because of the increase in energy, stamina and resilience it indicates. But it would not be necessary that the person actually return to work, only that they be capable of it, for this to represent a health outcome. The outcome is not 'work', but the restored capacity for activity to normal levels. Using 'work' as the outcome would miss out the people who had recovered but had not returned to work. 'Work' is therefore a bad proxy for the actual desired outcome, which is restored capacity. There are plenty of medical tools for measuring recovery from an illness; work is neither necessary nor adequate as a measure of recovery.

Nor is work appropriate as an expected, assumed or mandated goal for every person. Some people will never recover enough to be able to work, meaning that such a goal is simply setting them up to fail. Other people have other reasons why work is not appropriate, such as age or caring responsibilities. Some people are so far from work that, even if a return to work is theoretically possible, it is not an appropriate focus at this time. Some work, particularly at the bottom end of the labour market, is damaging to health and not amenable to improvement through CBT or other healthcare measures (Grove, 2006).

Mental health

Healthcare is important for people with MH conditions, but is very poorly provided. It is not just that GPs are rarely trained in MH and are difficult to access, but that the early-access scheme, Improving Access to Psychological Therapies, is experienced by mentally ill people as hindering access to psychological therapies. A&Es are overcrowded and under-resourced, making them a poor choice in a crisis, and mental health units are running higher than 100% capacity. Community Mental Health Teams are overworked, and as a consequence many people who need CMHTs are unable to get them. The provision of secondary mental health care is no longer an indicator of need, because so many who need it don't get it.

The long-term abandonment of people with mental health conditions means that many have progressed a long way past the point where services such as 'early intervention' or 'improving access to psychological therapies' (IAPT) can have any use. Even before that stage, at the point of seeing a GP, people find it can take weeks to get a GP appointment and even then it is with any GP, not their own, resulting in little to no continuity of care. It is typically necessary to physically attend the GP practice, which blocks those who most need help from accessing it. The mental health focus group reported that only one in ten GPs have specialist training in mental health and that GPs

rarely know what support is available let alone suitable. Altogether, GP surgeries were not able to provide a 'first stop' place to go to for either urgent or continuous care, making it far too common for people with mental illness to go unnoticed by the healthcare system.

Early intervention only works if it is just that – early in a person's illness. This is not the case when people struggle to get a GP appointment, or when GPs lack the training or the opportunity to refer to people to an appropriate level of support. The IAPT service was designed for people with mild-moderate depression or anxiety, not for people whose depression or anxiety was chronic or severe, nor for people who had other mental health conditions. Whilst early intervention is important, it is even more important that there be good quality, long-lasting therapy available for those whose conditions are not 'mild-moderate depression or anxiety'.

The Cognitive Behavioural Therapy (CBT) that is on offer under IAPT is not appropriate for everyone. Recovery rates for IAPT are based upon those people who complete a course of treatment, leaving out those who drop-out part way through or who never make it to the first session; when these people are included, the IAPT recovery rate for people identified as in need of psychological therapy is under 10%. CBT can be helpful for people with job-related depression or anxiety, but only if they have high control over their work (Seymour & Grove, 2005). People in bad jobs with high pressure and low autonomy may not benefit from CBT, and as such IAPT may function only to 'patch people up' to return them to work, but not to effect a long-term improvement in mental health, well-being or quality of life.

Barrett wrote that, "Many of the clients of the new IAPT services will be the casualties of a brutal capitalism that cares little for its workforce or for those who are disheartened and disillusioned by work" (Barrett, 2009). Support for people with mental health conditions needs to extend beyond the treatment of symptoms (mental illness) to measures that alleviate causes or exacerbators of mental illness – including poverty, bad jobs, and stigmatisation, all of which the government has responsibility for. For many people, depression and anxiety "are not an individual fault or pathology", nor merely due to misattribution or faulty thinking, but instead are "a realistic perception resulting from social and economic deprivation or being trapped in an abusive relationship" (Hall & Marzillier, 2010). Therapy that focusses upon changing how a person perceives a situation cannot be effective when a situation is genuinely negative, as is regrettably common. Hall and Marzillier concluded that "the assumption that mental health problems are exclusively attributes of the person ('symptoms' in the language of medicine) and that with appropriate help individuals can overcome their problems ('get better') needs to be challenged."

The government says it wants us to work yet puts every barrier in place; every barrier they can think of to stop us, they put in.

There is grave concern about the use of paid employment as a goal and measure of treatment success, with psychologists pointing out that "the outcomes of therapy are not predicable and cannot, and should not, be predetermined – in fact, that is the point" (Thomas, 2013). Successful therapy depends upon achieving a good alliance between therapist and patient, and this alliance itself depends upon collaboration, common goals

and a positive affective bond. Where patients feel that a goal of returning to work is being imposed upon them by the therapist or service, this damages the relationship between them and may prevent any improvement in health and wellbeing. The focus of governments upon employment, and the design of health treatment around this goal, simultaneously misunderstands the nature and process of treatment, and fails the people the government claims to help.

Mental health treatment needs to move away from a narrow focus on 'curing' people where 'cure' is synonymous with 'in work'. Instead, it should be focusing upon 'care', and on improving the person's quality of life. Mental health professionals use the term 'recovery model' to refer to an approach that focuses on building resilience and quality of life, "with an emphasis on long-term contact that may not be aimed at achieving positive change in conventional outcome terms" (Hall & Marzillier, 2009). Services need to be available both at a crisis point and long-term, to ensure that an improvement in mental health and/or quality of life is sustained.

The MH focus group were emphatic that healthcare must be kept separate from work. This was the point which they spoke most strongly on and returned to the most often. At the moment, GP surgeries are a safe place to attend and discuss health in confidence with a doctor. Incorporating JobCentre staff into GP surgeries would render them unsafe for people with MH conditions. The 2010-16 government had broken their trust in the government and the DWP, and any link between the DWP and the NHS was frightening to them. Any attempt to create such a link would undermine the relationship between a doctor and their patient, and could lead to people keeping away from necessary contact with their GPs.

The group concluded that there must be no link between the NHS or Department for Health and the DWP. There must be no suggestion that work is a health outcome, and no expectation that work be considered a goal of medical treatment. The two are distinctly separate, other than in the simple observation that good health makes work more possible.

As Hall and Marzillier say,

"Psychology provides a knowledge base that has implications for mental health far beyond the quasi-medical models that underpin therapies like CBT (see Gilbert, this issue). For example, the assumption that mental health problems are exclusively attributes of the person ('symptoms' in the language of medicine) and that with appropriate help individuals can overcome their problems ('get better') needs to be challenged. The major mental health problems, anxiety and depression, should be seen in the context of growing income inequalities, changing patterns of family life, increasing job insecurity, the influence of the media on people's expectations and wants, social pressures and stresses, as well as a range of physical conditions and illnesses that directly and indirectly affect mood and well-being.

The existence of sick people who are working is not evidence that all sick people can or should work, in the same way that the existence of healthy unemployed people does not mean that everyone should give up work straight away. The relationship is deeper and more complicated than that... It is important that psychologists point out that, for many, depression and anxiety are products of the society in which they live and are not an individual fault or pathology. A sense of powerlessness, commonly part of depression but also prevalent in many other conditions, is not just a problem of misattribution or faulty thinking. Sometimes it is a realistic perception resulting from social and economic deprivation or being trapped in an abusive relationship."

Final recommendation

The problem is not that sick people are out of work. The problem is that sick people are sick. That society then insists those people live in poverty because they are not in work does not mean that work will make these people well.

Work is not a health outcome, nor a health goal. Good health is a health outcome, and self-chosen activities can be health goals. But work can be actively harmful, whether because it is bad work in and of itself, or because an individual does not have the health necessary to sustain work. The government should be aiming to ensure that every person, whether in work or not, can obtain the benefits that can come from work - time structure, social contact, collective purpose, activity, identity/status and freedom from financial strain. This is particularly important for people with chronic illness or disability for whom work is impossible, detrimental or unreasonable.

Conclusion

People with chronic illnesses or disabilities need to be supported to live independent lives outside of the workplace before the government can expect them to consider paid employment. If the necessary support is not available for personal care, household tasks and caring responsibilities then sick and disabled people will not have the capacity for work. These things must be put in place first.

Sick and disabled people, like all people, have a right to rest and leisure. Any paid work must not be so exhausting as to deprive people of their right to free time. This applies equally to otherwise 'healthy' people who are over-burdened by the amount and/or nature of the work that they do. The government must give consideration to the overall wellbeing of the citizens it governs.

For many disabled people, unemployment is due to barriers in society. These include difficulties in getting around, and not having the support they need in the workplace. The government is responsible for ensuring that these barriers are removed so that disabled people can participate in society on an equal basis with non-disabled people. This includes, but is not limited to, transport, assistive technology, physically adapted work places/stations, support workers, supported employment and job brokers.

For many chronically ill people, unemployment is due to a lack of physical, emotional and/or cognitive capacity. They simply do not have the capacity to participate in activity to the same level as healthy people. Consequently, basic activities of daily living plus the fulfilment of the human right to rest and leisure may take up all of a person's capacity for activity. Whatever capacity is left over is rarely at a sufficiently high, reliable and consistent level to make a person employable. The government must recognise that there are many chronically sick people who do not need employment support, but do still need support to live as full members of society.

Some chronically ill people are only moderately ill, leaving them with reliable and consistent capacity for part-time work. These people still need support in the work place, in particular to have financial protection and protection against disciplinary procedures for leave taken because of their underlying illness. They may need other measures, such as shorter shifts or more rest breaks. They are likely to need a top-up benefit, but crucially it must not be provided under any compulsion or expectation that the individual will seek to increase his or her hours. Given the stringency of the WCA, these people may be more likely to be found on Jobseeker's Allowance than on Employment and Support Allowance.

Chapter Two: A new benefit

The purpose of sickness benefits

Before a critique of the sickness benefits system, and the development of a better one, can be made, it is necessary to understand what a sickness benefit is for.

Sickness benefits are an alternative to jobseeker's benefits. People who are out of work but able to work and looking for work are eligible to claim a jobseeker's benefit, which is paid on the condition that they do in fact look for work and take up any reasonable job offer. The purpose of a sickness benefit is to provide an income replacement for people who cannot work due to their health, and who therefore cannot claim a jobseeker's benefit. A sickness benefit can also provide opportunities for rehabilitation, both medically and vocationally, to assist those who could work in the future if they got the right support now.

People with illness or disability that makes work difficult, unreasonable or impossible for them tend to be on benefits for long periods of time; for many people with permanent disabling illness, they will not be able to leave a sickness benefit until they reach pension age. For these people, a sickness benefit is their lifetime income. It is supposed to protect them from poverty, in recognition that they have no recourse to other means of income because they cannot work. The sickness benefit is supposed to be at a level adequate for social participation, to ensure that sick and disabled people who cannot work are not excluded from society through the triple means of illness, worklessness and poverty. It should also be stable, in order to ensure income security for people who otherwise can lead precarious lives.

The purpose of a sickness benefit, therefore, is to provide an adequate income for people who cannot work due to sickness or disability.

The current UK situation

In the UK, there are two out-of-work benefits, Jobseeker's Allowance (JSA) and Employment and Support Allowance (ESA). JSA is for people who want to work and are looking for work, but who currently don't have any work or have less than 16 hours of work a week. It comes with a range of conditions, specifically that jobseekers must spend 35 documentable hours looking for work each week (including bank holidays and public holidays), must apply for six jobs each week, must do anything their work coach tells them to, and must attend the jobcentre once a fortnight to demonstrate their compliance with these rules. Any infringement – such as applying for only five jobs, or being late to attend the jobcentre meeting by five minutes – results in sanctions. A sanction starts at the loss of benefit for four weeks, and extends to the loss of benefit for three years. It is the complete loss of benefit. The jobseeker must continue to comply with the rules of benefit during the time that benefit is not paid; if he does not, additional sanctions are applied. These rules are applied to people on JSA to ensure that it meets its purpose – providing an income-replacement to those who want to work, and intend to work – and does not end up subsidising people who don't want to work.

Employment and Support Allowance is the UK's current sickness benefit for people who are deemed too sick or disabled for it to be reasonable to expect them to work. Because people on sickness benefit have been assessed as unable to work, they are not required to look for work, apply for jobs or take up job offers. However, in the UK they may be required to engage in activity that has been defined by the government as 'related to work'. These people are placed in the Work-Related Activity Group of ESA,

and they receive less money than the people in the Support Group of ESA (who are not required to take part in activity in return for their benefit). However, Work-Related Activity (WRA) was never defined in legislation or guidance, nor has any indication been given of what it means to be capable of WRA whilst being incapable of work. Consequently, it has been left to claimants and assessors to guess the meaning and purpose of this group. The current political explanation is that this group is for people who are expected to recover or otherwise become able to work in the future. These people are therefore supported to remain near the job market, ready to get a job once they become able to work. They are required to engage in such support as is offered as a condition of receiving their benefit.

The criteria separating the WRA Group from the Support Group are not based on how likely a sick or disabled person is to be able to work in the near future, nor on the extent of support needed to be able to work. There is no evidence suggesting that people in the WRA group are any closer or more able to work than people in the Support group; instead, what evidence there is suggests there is no difference in current or future work capacity between the two groups (Barnes, et al., 2011). People with degenerative conditions who currently cannot work but who don't meet the criteria for Support Group are placed in WRAG, despite the fact that they are not going to be able to return to work. Because the criteria for distinguishing between the two are ambiguous in relation to capacity for work, the nature and duration of support cannot be identified and neither can suitable activity requirements. The result is that people in ESA WRAG are no nearer work than are people in the Support Group, but are required to engage in activity that has been found to be unhelpful, irrelevant and detrimental as a condition of receiving their benefit (Hale, 2014; Benstead & Nock, 2016).

ESA and the WCA have come under significant criticism since their introduction in 2008. The Labour government, before it lost the general election of 2010, was aware that ESA was not working as intended. However, the election occurred before Labour was able to take steps to remedy the situation. The 2010-15 Conservative/Liberal Democrat made the decision to extend ESA to people who were at the time receiving ESA's precursor, Incapacity Benefit. This decision was made in the face of independent advice to the government that ESA was not fit for purpose and should not be extended at that time (Marsh, 2013).

Initial recommendation

The respondents to Ekklesia's survey were strongly in favour of a sickness benefit for people who currently were unable to work, struggled to work or needed support to work. The results were ambiguous as regards having sub-groups within a new sickness benefit, as currently is the case for ESA. There was some support in Ekklesia's survey results to have subgroups within ESA for people who could work at least part-time, or could work in the future if they had training or other support now. Between 46% and 56% thought that specific groups within a sickness benefit to cater for these differing needs might be acceptable, although one in five thought they should all be in a general group that did not have any requirement to engage. At the same time, the majority of respondents to the survey were strongly against sanctions and conditionality.

On the whole your survey is quite well rounded, but I take issue with being asked, as a mental health sufferer, to pass comment on which band of payment should be allocated to sufferers of different types of condition. I am unqualified for that judgement.

Because the respondents were strongly against conditionality, we did not recommend that there be strict subgroups within a sickness benefit as there is for ESA. If there are no conditions attached to a sickness benefit, then sub-groups within it serve no practical purpose. We therefore highlighted some of the different reasons a person might be on sickness benefit as being potentially indicative of the type of support a person might need, but did not recommend that there be sub-groups based on these differences.

I put a lot of ticks in "tailored group" on question 29. This is because there should be lots of tailoring - and that tailoring shouldn't generally be a general requirement to do work-ish things, but to do things that are actually constructive, and shouldn't have hard conditionality - a requirement to engage, but no hair-trigger (or even vaguely easily triggered) sanctions. The requirement to engage should not be burdensome - it should be tailored by category and to the individual, with negotiation to work out what they can do without undue burden.

There should never be any pressure or financial sanctions applied against those who are sick or disabled in any circumstances. There should never be a 'requirement to engage'. Remembering that benefit fraud is a tiny fraction of claims, the exception and never the rule, allows a proportionate response to genuine people in desperate need of help.

Mental Health

The MH focus group concluded that the 'end goal' of a benefit for people with MH conditions should be to protect their quality of life. A benefit that included measures that impeded their quality of life – such as repeated assessments, conditionality requirements and poverty-level income – was not appropriate or acceptable. When someone is too sick to work, the focus should be on health, not on work. By having quality of life as the end goal, strategies for moving towards and into work would be included where they are appropriate, and not included if they would be inappropriate or harmful.

For people who had a mental illness and some capacity for work, it was still felt that the main goal of a sickness benefit – as with the health service – is to promote health and quality of life. Because of the difficulties of living with mental illness, there should be no compulsion to work. What is needed is support for life, not sanctions to work.

The group did not want to see different benefits for people with different disability or illness types. People can have multiple illnesses or disabilities and it is not possible to pigeon-hole different people into discrete groups. There will always be some overlap, such that the only appropriate distinction is between those who can work and look for work (Jobseeker's Allowance) and those who, for health reasons, should be considered as unable to work or unable to look for work (sickness benefit).

Physical Health

The physical health group reported similar needs to the mental health group: they needed to be able to focus on managing their health and their quality of life. They were not well enough to work or to consider work. They were well aware of the benefits that can be gained from work, but this awareness bore no relation to their physical capacity. What they needed from a social security benefit was an adequate income coupled with financial security – free from sanctions and reassessments.

Brain Injury

Again, the main need of this group was the adequate finances and long-term stability of a sickness pension. They could not comply with Jobseeker's Allowance conditions due to their cognitive fatigue, poor recollection and low capacity for activity. These were largely unchanging problems caused by their brain injury, which rendered them incapable of work and therefore dependent upon out-of-work benefits. They were not going to improve, and therefore a group like the Work-Related Activity Group, which assumes a future capacity for work, was not appropriate.

Learning Disability

The learning disabled group reported that they struggled with conditionality. Available data confirms that people with learning disabilities are much more likely to be sanctioned than healthy, able-bodied people despite the fact that they need more support to find and sustain work (Oakley, 2014). This suggests that JobCentre staff are not capable of tailoring conditionality appropriately to the needs of the people they see. The group reported that they did not get support from Job Centre or Work Programme staff, but only from the local church which ran a support group for them. In terms of benefits, therefore, they also needed an adequate income free from the risk of being lost due to sanctions or flawed reassessment.

They reported that they had appreciated Remploy and the employment opportunities it offered, and such supported employment was what they wanted and needed if they were to work in the future. The Work-Related Activity Group was therefore inappropriate for them, as it was not they who needed to change, but the work-place.

Visual Impairment

The RNIB caseworkers indicated that people with visual impairment are typically capable of work when one considers strictly their physical and cognitive capacity. However, the work they can do is restricted in nature and often in hours, and requires support such as transport to work and accessible technology. The blind people I spoke with explained that some blind people, particularly those who had not grown up blind and with access to computers, also struggled to work at the same pace as sighted people or some young blind adults. They largely wanted to work, but lacked either the capacity or the support and opportunity they needed if they were to be able to work.

What blind people need is different from what the Work-Related Activity Group was set up for. The WRAG was intended for people who could not work now, but might be able to work in the future. The assistance offered in WRAG includes things like CV writing, interview skills and confidence building. These are not the barriers that are blocking blind people from work. What blind people face is a paucity of support from the government or from employers, such that they do not get offered jobs and do not get

the necessary support to search for, obtain and stay in work. Therefore what blind people need is not teaching about motivation or sessions on CV writing, but the guarantee from the government of adequate support such as transport to work and assistive technology. They did not need sanctions to make them look for work, because it was not a lack of effort on their part but a lack of support from the government that was keeping them from work.

Work search requirements typical of JSA, and activity requirements of ESA WRAG, were not appropriate for these people who could not search and apply for work in typical ways, and who were at a disadvantage – due to the in-work support they needed – when being considered by employers. Therefore, the only appropriate benefit group was ESA Support Group. It was largely felt that if the appropriate support was given, then they would naturally obtain employment without any threat being necessary. If they remained on ESA for a long time it was not because of an attitude of worklessness or the need for a threat, but because the State had failed to provide the necessary and appropriate support. Therefore, there was no reason not to give these people a benefit free from threat.

They did not want separate benefits for blind and other disabled people, compared to people with chronic illness. They pointed out that blind people and other disabled people could also have chronic illness, which would make separate benefits confusing. The essential need remained the same: that the person could not work in the open labour market, whether that was at all, at the current time, or without support.

Hearing Impairment

The deaf group reported that they struggled to obtain work they could do because of employers' - usually unfounded - concerns about health and safety and what they were insured for. They had been refused jobs on the grounds of health and safety, although they suspected that this would count as discrimination and was unlawful. They also struggled with public transport because of the paucity of clear visual announcements. JobCentres and Work Programme providers were of no help; the only help they got was from the deaf people's charity that they attended. Again, the issue was not the motivation to work but the lack of provision of support.

Because of these issues, deaf people tended to be on out-of-work benefits for long periods of time, and JSA conditionality requirements were not appropriate for them. What they needed was a benefit set at an adequate level off which to live, without conditions, and with a job broker to find them work. As with blind people and learning disabled people, it was not the deaf person that needed to 'upskill' in order to become employable, but the labour market that needed to change in order to take on deaf people.

Final recommendation

The purpose of a new sickness benefit should be to provide adequate income-replacement to people who, due to their illness or disability, either: cannot reasonably be expected to work; or might be able to work but need support and freedom from sanctions to help them find work. The criteria for sickness benefit should therefore be that, because of illness or disability, an individual cannot work and/or compete for work in the open labour market. The associated financial support should be set at a level adequate for long-term social participation, and should not be vulnerable to removal through either sanction or re-assessment.

This new sickness benefit should consist of one group only, regardless of the health reason for needing that benefit. It was recognised that there could be different reasons for needing sickness benefit, particularly between disabled people whose main barrier was the lack of provision of support to look for or stay in work, and chronically sick people whose main barrier was lack of capacity for activity generally, which was not amenable to any support measures. At the same time, it was pointed out that people could have multiple health conditions and therefore a variety of different support needs, which makes it inappropriate to pigeon-hole sick and disabled people into different intra-benefit groups.

Income

Under ESA, sick and disabled people are kept on poverty-level incomes until they reach retirement age, at which point they receive the means-tested state benefit, which is adequate for social participation for pensioners. The minimum income, excluding housing costs, for single people is estimated to be £198.85/week (Davis, et al., 2016); the Work-Related Activity Group of ESA is half of that, and is being reduced to £73.10/week from April 2017. This is 39% of what they need, and is exacerbated by having to use some of this money to top-up rent. The Support Group gets £109.30/week – 55% of what they need. In contrast, a pension-age couple receive 98% of what they need (Davis, et al., 2016). The sickness benefit therefore fails its prime purpose of protecting sick and disabled people from poverty.

Neo-liberal politics appears to assume that only the manifest benefit of employment, freedom from financial strain, exists. Thus, their policy focusses on reducing income available to people out of work, and increasing the income available to those in work. The aim of this policy is to ensure that people choose to work for an income (on the basis that it is higher), rather than choose to claim benefits (because benefits don't require effort). But the evidence available tells us that it is not just money that people want from their work; and claiming benefits does require effort – jobseekers have to have documented evidence that they have spent 35 hours every week looking for work, and that they have applied for six jobs every week, in order to retain their benefit. There are factors other than income that are involved in whether or not people work; arguably, the predominant causal factor is simply that there aren't enough jobs (Shildrick, et al., 2012). Consequently, a focus on income is at best irrelevant (people would be in work if jobs were available) and at worst harmful (people who are out-of-work are consigned to destitution).

Living in poverty is bad for health. This should be obvious; people who cannot afford decent food, housing and other necessities will suffer as a consequence of not being able to meet their needs. This could be through a variety of mechanisms be it malnourishment, malnutrition, respiratory conditions, reduced hygiene, untreated illness or chronic stress. None of the income-replacement benefits meet the level needed for short-term subsistence living, with the consequence that people are put in positions where they cannot buy what they need for long-term health management. Such poverty is time consuming and expensive. Without an adequate income, people must spend large amounts of time hunting for the cheapest products, but are unable to use multi-buy offers or purchase bulk items because, although cheaper in the long-term, the money isn't there in the short-term. People have to choose between going hungry and going cold, both with significant health impacts. Transport is expensive, so many miles must be walked, but without the necessary sustenance or weather proof clothing.

Extra money can help people. People who received Return to Work Credit reported being “free from financial worry and stress” and the positive impact this had on their health (Corden & Nice, 2006c). Such “worry and stress” saps the brain of its cognitive capacity; it is not that poor people have less cognitive capacity, but that poverty reduces how much is available (Mullainathan & Shafir, 2013). Poverty reduces cognitive capacity “more than going one full night without sleep” (Mullainathan & Shafir, 2013). Anxiety and depression develop, not because of a psychiatric deficit, but because of “severe environmental deficits”, i.e. poverty (Baer, et al., 2012), and “a realistic perception resulting from social and economic deprivation” (Hall & Marzillier, 2009).

Despite concerns that people claim benefits because the relative income of benefits compared to (minimum) wages is too high, increasing the value of work via Return to Work tax credits did not increase the proportion of sick people moving from sickness benefits into work (Corden & Nice, 2006c). Although the extra money was useful in paying off debts and providing reassurance, it was not a key reason for returning to work – most of those who returned to work did so because their health improved. On the other hand, people do return to work before they are well enough, or continue to attend work whilst ill, because they cannot afford to live on sick pay (Ashby & Mahdon, 2010; Irvine, 2011). Higher benefits allow those claimants who can work to wait for a better job match, resulting ultimately in higher productivity (Krueger & Meyer, 2002; Corden & Nice, 2006c). From this perspective, sick pay and sickness benefits should be higher, to promote fuller recovery and more sustainable returns to work (Krueger & Meyer, 2002; Corden & Nice, 2006c).

Higher benefit levels can therefore assist unemployed people in a myriad of ways: they become better able to purchase necessities including food and adequate housing; they are subject to less stress regarding both short-term and long-term need; and they have the disposable income to take care of their health. This allows them to wait for a job opportunity and adequate level of health that will allow them to work without making themselves more ill or preventing further improvement. In turn, this makes it more feasible for a person to move out of the low pay/no pay cycle and a pattern of recurrent sick leave, into a higher-level job with improved pay and prospects. Such an outcome is favourable not just for the individual, but for their dependent children and for the economy as a whole. The economy gains from the marginal propensity to consume of an individual who is lifted out of poverty, and from the reduced healthcare for a person who can now afford to live in a way that promotes rather than harms health. Adequate levels of benefits should therefore be seen as a social good, not a social evil.

Benefit should be paid promptly. The current policy of not paying ESA for the first few days of the claim is misguided. Many people will have already had a period of unpaid sick leave as part of their leave from work, often for much longer than the three days legislated for the beginning of Statutory Sick Pay (Adams, et al., 2015). Others will have come from Jobseeker’s Allowance, and there is no reason to remove their benefit for a few days simply because the type of benefit they receive has changed. Further delay due to administration should be minimised as much as possible; it should not take any more than one week – if that long – to pay someone the benefit they need to live.

Taking £30 per week from those unfortunate enough to be sick is nothing short of malicious, it will save some money on one budget sheet but consequential costs will more than cancel any cash benefit. Denying sick people money will certainly not (a) make them well or (b) magic them in to work.

Conditions whilst on benefits

Current situation

On top of the strain of not being able to afford necessities, people with chronic illness or disability must also comply with benefit regimes. This means frequent attendance at JobCentres, Work Programme providers and unpaid work placements. Being late, for example because buses were late or because of a long queue at the JobCentre sign-on desk, is met with fixed sanctions. Non-attendance due to a family funeral, incapacity or not applying for jobs on a public holiday also receives sanctions (Rickman & McKernan, 2015). Three-quarters of Jobseeker Allowance sanctions and half of all ESA sanctions that are challenged are overturned (Webster, 2016), but it is too late by then; people have already had to take out loans to cover the loss of social security (Salford City Partnership, 2016). The strain this creates, both through the fear and distress and the effort expended on trying to fulfill requirements, causes chronically ill and disabled people's health to get worse (Hale, 2014; Low, et al., 2015; Salford City Partnership, 2016).

It is well established that sanctions have negative effects. They prevent individuals from developing positive, trusting relationships with their adviser (Nevile & Lohmann, 2011; Meershoek, 2012). They reinforce disadvantage, by pushing people off benefits who have nowhere else to turn, and by forcing people to take inappropriate, poorly paid and insecure jobs (Arni, et al., 2009; Griggs & Evans, 2010). They force people to take part in activity that is detrimental to their health, because the alternative – a loss of income – is even worse. They result in a JobCentre that, rather than acting as an active employment agency, behaves instead as a punitive policer of behaviour.

The conditions imposed upon sick and disabled people do not even have the merit of being helpful. Services offered tend to focus on 'workplace' skills such as CV writing, interview technique, confidence and motivation (Hale, 2014). Next to no-one receives job-specific training, and fewer than one in five receive any support specialised to their condition (Hale, 2014). Yet when asked, only one in five chronically ill people reported that such support for 'workplace' skills might help them to find suitable work; in contrast, 66% said the best assistance would be an end to conditions and sanctions (Benstead & Nock, 2016).

Imposed activity requirements can push people away from work. For sick and disabled people, this is in part due to worsened health caused by being forced to engage in excessive or inappropriate activity (Hale, 2014). But on top of this, activity requirements "can even reduce employment chances by limiting the time available for job search and by failing to provide the skills and experience valued by employers" (Crisp & Fletcher, 2008). Indeed, the USA is moving away from "basic workfare programmes" because such programmes "have not provided clients with multiple barriers with the additional support they need to find employment" (ibid.).

A forthcoming research paper concluded that, "assessment & support are critical for the implementation of conditionality for disabled people" (Baumberg-Geiger,

in press). Requirements to participate in activity are, in most countries, based upon having adequate assessment and good support for people with chronic illness or disability. In contrast, the UK has both poor assessment and support, and high levels of conditions and sanctions. There is significant evidence suggesting that benefit sanctions as used in the UK are harmful to people with chronic illness or disability.

There is no evidence to suggest that sanctions are needed to make people with chronic illness or disability work. The problems that sick and disabled people face are not ones of inadequate motivation (Kemp & Davidson, 2010; Ali, et al., 2011; Kirsh, et al., 2012). Rather, they are structural problems with the support that the government and employers are willing to provide. It is not the sick or disabled people's behaviour which needs to change, but the behaviour of employers and of the government.

Initial recommendation

I recommended that sickness benefits are awarded without condition. Sick and disabled people do not lack the motivation to work; what they lack is the health and/or the necessary support. Sanctions are detrimental to them and drive them further away from being able to work.

Mental Health

The mental health group felt very strongly that there could be no coercion to make sick people work, in the same way that medical treatment cannot ethically be forced onto people. JobCentre Plus and Work Programme staff were not sufficiently qualified to prescribe activity for people with chronic illness, especially for mental health conditions where a feeling of safety can be vital. JobCentre Plus and Work Programme staff were reported to lack the ability or knowledge to provide any useful support, making the requirement to engage and threat of benefit loss even more futile.

Similarly, GPs must not be asked by the government to prescribe work coaching to their patients. This was felt to be coercive, which would result in severely sick individuals disengaging from their health service. GPs have some knowledge of health conditions, albeit often lacking the specificity required for mental health conditions, but they do not know what support is available in terms of work or work-related activity. Nor are they trained in Occupational Therapy or community mental health support, both of which constitute separate professional specialisations. GPs work under the principle of 'first do no harm', a crucial safeguard when caring for vulnerable and severely ill people. GPs therefore cannot prescribe work-related activity.

The coercion involved in mandating sick people to undertake prescribed activity was described as traumatic, consuming the whole life and crippling mentally ill people even further for months. The Improving Access to Psychological Therapies and Individual Placement and Support programmes were both experienced as further examples of coercion combined with insufficient support. IAPT is a programme designed to provide low-level Cognitive Behavioural Therapy to people with mild-moderate depression or anxiety; it is wholly unsuitable for people with severe and enduring mental health problems. The mental health group reported that the existence of IAPT blocked them from getting the depth and duration of mental health support that they needed if they were to stabilise their mental health and, ultimately, improve their lives. The IPS was seen as a coercive programme with an unhealthy emphasis on work which was not appropriate for people who were too ill at that time to be considering work.

What the mental health focus group reported that they needed was quality, appropriate, ongoing mental health care and support without time limit. They required a recognition that crises occur, reflecting other researchers' findings that chronically ill people do not follow a linear path to employment (Nevile & Lohmann, 2011). They particularly needed a freedom from the expectation of work or returning to work whilst their mental health was so unstable. They needed the space, time and support to stabilise their lives and work on their wellbeing and quality of life before they could be expected to consider moving towards paid work. Indeed, such provision would in itself be a major step towards work.

We discussed the possibility of having 'incentives' for people who engaged with work-related support. This would come in the form of a top-up benefit in return for taking part in a recommended activity. However, the group considered that this would be discriminatory against those people who were unable to engage with measures to return to work. It was felt that reimbursement for expenses related to participation, such as travel costs, would be appropriate. This would ensure that those who are able to participate in support would not be effectively financially worse off as a result.

Physical Health

The physical health group were not in a position to be able to comply with benefit conditions because they were not well enough to carry out excess activity on top of managing their illness and personal needs. Activity requirements in general were detrimental because they prevented chronically ill people from conserving their energy for more necessary and appropriate tasks. It is particularly important that sick people are not asked to engage in prescribed activity because of the substantial risk of forcing a person to undertake activity that is harmful to them. This is the case even when the prescribing officer is medically trained and has significant experience as regards the capabilities of sick people. There is simply too much risk of harm through such an approach.

As with the mental health group, the most appropriate prescribed 'activity' was the space to stabilise one's life and manage one's health without the stress of poverty or the fear of deeper destitution.

I'd like to see all compulsory work-related activity abolished for anyone pronounced unfit for work but a voluntary system put in place that is able to offer practical employment advice and retraining carefully tailored to the health, education and work background of each individual.

Brain Injury

The brain injury group reported that those who applied for jobs had been accused by the JobCentre of 'sabotaging' their job application by disclosing their brain injury; however, if they did not disclose their brain injury, they could not then rely on the Equality Act 2010, because the employer would not know they had a protected characteristic. They were therefore placed in an impossible situation if they did apply for jobs – which they typically only did because they were required to do so under JSA, not because they were well enough to work – in that the JobCentre expected them to withhold crucial information from a prospective employer.

As with the other focus groups, the only support they got was from their dedicated local charity, where the staff were specialised in the illness, injury or impairment the charity was set up to support. The JobCentre, Work Programme and WCA staff were reported to be uniformly ill-informed regarding the impact of brain injury and unqualified to offer assessment, advice or support to people with brain injury. Consequently, conditionality was wholly inappropriate, because the employment advisers setting the conditions did not know what a person with brain injury could reasonably be asked to do. The group concluded that in practice it was not appropriate to put conditions on a person with brain injury, because they were unlikely to be able to meet them and would not benefit from doing so.

They don't understand your medical condition or what's wrong with you, and they just don't care.

Learning disability

The learning disability group reported that they experienced the ESA Support Group as a safe place to be, giving them the choice and the time to look for work at their pace and in ways suitable to them. Being in the Support Group also ensured that they had the space and stability to deal with life events as they came up, which condition-based benefits lacked the flexibility to do.

The group struggled to understand the benefits system, let alone conditionality, and as a consequence were vulnerable both to over-claiming and subsequently having money removed, or under-claiming and not receiving the money they needed. The DWP and JobCentre were typically unable to explain what was going on with an individual's benefits when that individual did not understand what was going on either. They reported being sanctioned for reasons they did not understand, or because of administration errors at the DWP's or JobCentre's end. Sanctions put them into crisis as a consequence of both the penury it induced and the anxiety of being in a system they were unable to understand.

The Work-Related Activity Group just gives people trouble and hassle.

Visual Impairment

The blind caseworkers and people I spoke with reported that conditions for JSA are inappropriate for visually impaired people, because they cannot seek work at the same pace as an able-bodied person nor for the same amount of time (JSA claimants have to spend 35 hours a week looking for work). Difficulties with public transport make fortnightly sign-ons inappropriate, both because of the time it consumes and because of the extra difficulties caused if a bus or train is late or cancelled, or if the person misses a stop due to the lack of auditory announcements.

Jobcentre staff lacked the knowledge or ability to assist visually impaired people to look for work in accessible and appropriate ways, and would instead require the person to search for work in ways that assume good vision. For example, blind people were expected to sign claimant commitments which they could not read and had not had read out to them; and to read technical (print) books in libraries.

The impact of the conditionality regime was that blind people would develop mental health problems as a consequence of the pressure they were put under to perform activities they were not capable of doing, and the threat of losing their income. The lack of understanding they experienced from JobCentre and Maximus staff caused significant distress. Blind people felt insulted and pressurised by staff who would refer to their 'good eye contact' or ask if they could drive. Such comments give the impression that staff do not pay attention to the person whom they are with, and are unaware of or insensitive to their needs. This is not something that can be adequately addressed by a few days' training; blind people need staff with several years' experience of working with blind people in their daily lives, accessing support services and at work.

Hearing Impairment

The deaf focus group reported experiencing sanctions whilst on Jobseeker's Allowance because British Sign Language interpreters were not provided for JobCentre or Work Programme meetings, and consequently the deaf person could not take part in what was supposed to be a one-to-one meeting with an employment adviser. The JobCentre provided no help in terms of moving towards work or getting work, and did not provide any interpretation of either spoken or written English for its deaf clientele. One person reported that they ended up over-claiming benefits when their circumstances changed, because their poor understanding of English as a deaf person meant that they did not understand the benefits system they were in. The only help the deaf focus group reported getting was from specialist local charities, which were nationally rare and suffering from government cuts, and sometimes from friends and family.

The deaf group did not report objecting to having benefit conditions in principle. However, Jobseeker's Allowance was not suitable for them because of the extent of its conditionality and their difficulty as British Sign Language users in understanding and sometimes complying with the conditions placed on them. They needed a safe, stable benefit that would give them the time to focus on finding work rather than on managing poverty and jobseeker conditionality.

Other respondents

The individual respondents to the consultation were strongly opposed to conditionality and sanctions. It was commonly argued that sanctions are unnecessary - sick and disabled people generally wanted to work even when they couldn't actually work; inappropriate - the required activities are typically unsuitable and irrelevant; and harmful - the required activity drains physical energy and health, and causes mental stress and distress, whilst the threat of or actual loss of money also caused stress and want.

The respondents were also opposed to the idea of using top-ups as compensation for working with an employment support worker. It was considered to be discriminatory, and also unnecessary given people's natural desire to work. Reimbursement of expenses should occur, but incentives should not.

Sanctions are counter-productive, destabilising and damaging [sic] any relationships with caseworkers. They do create barriers to work, causing financial pressure and instability and the knock-on effects to mental and physical health.

The vast majority of claimants are highly motivated to work and happy to take part in meaningful, non-punitive employment support.

We totally oppose the imposition of welfare benefit conditionality and the use of sanctions for people that are claiming ESA. There should be no compulsory work related activity. The presumption that people will not look for work without the risk of punishment is based on a myth of benefits as a lifestyle choice.

Respondents raised the issue of Universal Credit. UC removes the bureaucracy of transferring from ESA to Working Tax Credit once the 16hrs/week Permitted Work limit has been reached, and removes the financial cliff-edge for claimants who work fewer than 16 hours and earn more than the minimum wage per hour. But it introduces conditionality and the expectation that claimants continually seek to increase their hours and/or pay until they eventually leave benefit. This is, as the DWP itself said, a new step. No other country applies the risk of sanctions to people who are in work and on low incomes. The DWP has not yet assessed the risks of harm this poses for healthy, able-bodied workers, nor how to adequately protect against such harm. For sick and disabled people who are at the limit of what they can do, no consideration has been given to how to identify how much an individual person can do and how to protect them from pressure to do more. Consequently, there is grave risk of harm to sick and disabled people who are at the limit of what they can do and need a top-up for their income to raise it to adequate levels. Sick and disabled people must not be under compulsion to increase their hours or wages of work.

Respondents agreed that sick and disabled people should be able to take part in voluntary work without sanction or loss of benefit. Voluntary work, unlike CV writing, is a productive use of time. It has the additional benefit of helping those who struggle to work to engage in some activity without pressure; and helping others to establish what capacity for work they do have and, if they are able, to then progress to paid work.

Allowing individuals to engage in voluntary work without penalty is undoubtedly an efficient and effective way to assist those with chronic illness to contribute to society.

Final recommendation

A sickness benefit should not have conditions and sanctions attached to it. Sick and disabled people do not need the threat of (further) financial poverty to make them want to work; predominantly, sick people need good health, and disabled people need practical support from the government and from prospective employers. There is therefore no positive need for conditions and sanctions.

Conditions and sanctions cause harm to sick and disabled people. They remove necessary money from people who have no other means of income and who often are not at fault for an alleged lack of compliance. They place stress on people who already have to deal with the combination of ill health or disability, and the lack of provision in society for their needs. Sanctions cause people to engage in activity that is at best

irrelevant and at worst actively harmful, both by damaging health through inappropriate activity and by preventing sick or disabled people from using that time and energy for a productive purpose. It is unlikely that employment advisers or 'Work Coaches' who determine conditions for sick and disabled people are qualified to make those decisions or recommendations.

Incentives are not appropriate because they discriminate against those unable to participate in support for work. Nor are they needed, because sick and disabled people do not lack motivation to work. This is in line with previous research that incentives do not influence a decision to return to work (Corden & Nice, 2006c).

Therefore, we conclude that a new sickness benefit should not come with the threat of sanctions or any requirement to engage in activity as a condition of receiving benefit.

Conclusion

Sickness benefits should provide sick and disabled people with enough money to achieve an adequate standard of living as defined by the Minimum Income Standard (Davis, et al., 2016). The benefit should be secure, so that sick and disabled people do not live in fear of being consigned to poverty. It should be provided as a right, in recognition that sick and disabled people are as much a part of society as are people in work, and that all people have a right to a decent standard of living and wellbeing.

The benefit should be available without conditionality or sanctions.

Conditionality is not appropriate for people whose main barriers to work are created by society, employers and the government. If decent jobs are available and the necessary support is provided, then those sick and disabled people who can work will naturally get and remain in paid work. Conditionality only drives people further away from work by causing them stress and reducing their opportunity to engage in productive uses of their time, including appropriate health care and management.

Chapter three: A new assessment process

This chapter builds upon the previous two chapters and the findings of the first two reports in this series to design a new sickness benefit and assessment process for sick and disabled people.

Initial sick leave

Current situation

The current UK sick pay scheme relies upon three (unemployed) or nine (employed) months of GP assessment before the state carries out its own assessment. Individuals have to attend their GP periodically to get a new sick note, and send that sick note to the DWP to confirm their ongoing eligibility for sickness benefits. There is no requirement on employees to attend occupational health assessments, or on the government or employers to provide OH assessments or put in place the recommendations of (voluntary) OH assessments. NHS waiting times are rising, delaying access to treatment that would lead to recovery. No consideration is given to factors at home or at work that need to change to permit a sustained return to work.

The DWP introduced an optional Occupational Health scheme (Fit for Work) to make recommendations to employers on reasonable adjustments that could allow a sick employee to undertake some work, but the way in which it has been implemented means that it has been of little to no practical use. Employers and GPs can refer patients to this scheme, but the sick employee cannot refer him or herself. The scheme was supposed to involve an hour's face-to-face discussion between the patient and Occupational Therapist, but the Treasury declined to fund this; instead, appointments are held over the telephone. There is no requirement that employers put in place the recommended adjustments; the recommendations tend in any case to be vague, generic and risk-averse (Tilley, 2015; Rushmore, 2015). There is particular concern for small businesses, for whom sick leave has a more adverse effect but who also may struggle to administer phased returns to work (Tilley, 2015; Hillage, et al., 2015).

The result of all this is that no prompt, efficacious action is taken to assist those who could try some form of return to work to actually do so. The DWP's own report on the performance of its Fit for Work pilots found that the most effective support occurred when employees had face-to-face access to a clinically-trained case worker, and when there was additional in-house support available (such as physiotherapy, counselling, anger management and benefits advice) (Hillage, 2012). But this is not what the DWP has done. The early and thorough intervention which international evidence shows is necessary is not available in the UK.

The process of claiming sick leave is, for most people, a long one (Bratsberg, et al., 2010). It is comparatively rare for a person to go from consistent full-time work to long-term sick leave in one step; cancer patients are a notable exception, but for most people the development of a severe illness is more prolonged. What tends to happen is that a person takes some time off work, returns to work and later takes some more time off, repeating this multiple times. This may also be punctuated with periods of unemployment. It typically takes six years from the first short-term sick leave to a person reaching long-term sickness benefits, usually via a "long and winding" path, which is rarely so "straightforward" as a "once-and-for-all health shock" (ibid.).

By the time someone reaches several continuous days of sick leave, it has often ceased to be 'early'. Sickness presenteeism (attending work whilst too sick to work

effectively) is a bigger issue in the UK than is sickness absenteeism. It not only prolongs a bout of sickness (Ashby & Mahdon, 2010; Garrow, 2016), it can also reduce productivity by a greater extent than taking some time off work would have done (Sainsbury Centre for Mental Health, 2007; Garrow, 2016). The 'Fit for Work' pilots between 2010 and 2013 recognised that sickness presentees are a key target group for early intervention; waiting until a person has been off sick for more than four weeks is comparatively late (Hillage, 2012). Sickness leaveism is also a growing issue, and one that masks from employers the true health of their workforce (Hesketh & Cooper, 2014).

Even at the early stages of becoming sick, it is rare that sickness is the sole issue. Employees taking sick leave often also experience difficulties with their employer, including harassment, bullying and a lack of support (Hillage, 2012). Financial difficulties create additional problems, as do poor housing and relationship breakdown (Hillage, 2012; Hillage, et al., 2015). In Fit for Work pilots, even though the participants were typically sickness presentees with common health problems - as opposed to people with severe intractable illness on sickness absence - the majority still reported that work made their health worse (Hillage, 2012; Hillage, et al., 2015). With multiple factors, including detrimental work, affecting the health of even those who 'just' have 'common' health problems and are largely still attending work, it should be clear that far more support is needed than a telephone-based basic occupational health assessment with simplistic, vague suggestions for those who have already taken four weeks off work.

Some of the illness present in the working-age population can be attributed to bad jobs. High job strain - the combination of high workload and pressure with low autonomy, personal control or decision latitude - can lead to mental illness (Michie & Williams, 2003; Sanderson & Andrews, 2006; Baumberg, 2011). The highly acclaimed Marmot Review concluded that "jobs that are insecure, low paid and that fail to protect employees from stress and danger make people ill" (Marmot, 2010). Employers including Amazon (Cadwalladr, 2013), JD Sports (Jenkins, 2016), Sports Direct (BISSC, 2016) and meat and poultry factories (EHRC, 2010) have all been exposed as bad workplaces. To remedy this, the appropriate approach is not to target the sick person but to improve the job market so that bad workplaces are not able to continue, and improve work so that it does not make people sick. Prevention is better than cure.

The wider economic environment also contributes to the extent of illness in the UK. Deteriorating employment opportunities can cause worsened health that eventually leads to long-term sickness benefits (Bratsberg, et al., 2010). This is from the effects of not just job loss and reduced access to jobs, but also an increase in pressure on those who remain in work, particularly in times of economic recession. A widespread poor economic performance in a given industry puts pressures on employees in surviving firms, who often find themselves facing the pressure of increased workload at the same time as higher risk of being made redundant (Rege, et al., 2005; Bratsberg, et al., 2010).

Job loss may make existing health conditions worse, or lead to new health problems (Kasl & Jones, 2002; Gallo, et al., 1999; Mandal & Roe, 2008; Brand, 2014). This is supported by objective health measures, including increases in mortality rates following job loss (Gallo, et al., 1999; Rege, et al., 2005; Sullivan & von Wachter, 2009). Mediating factors include the stress of inadequate finances and the emotional impact of job loss on self-worth and relationships.

Initial recommendation

I recommended that people continue to obtain initial sick leave by getting sick notes from their GP. This fits with the current accepted situation. The GP confirms that a person cannot work or struggles to work due to an illness, injury or impairment. This makes sense when one considers that the GP is the portal to most other forms of

healthcare, and is therefore usually the first port of call when a person feels ill and in need of treatment or therapy.

Mental Health

The mental health focus group was concerned that not everyone could get to a GP appointment. There are insufficient GPs to match demand and this can cause significant delays in getting an appointment and makes it difficult for people with chronic illnesses to repeatedly see the same GP. This lack of continuity hinders effective care and treatment for people with mental health conditions. There is insufficient time in a GP appointment to get to the root of a person's problems, and A&E departments - where many ended up having to go - were considered to be insensitive and unable to care for people with acute mental health problems. The group raised concern that the majority of GPs – 9 out of 10 – do not have specialised training in mental health conditions, and therefore are at risk of overestimating the capacity to work of a person with a mental health condition, and under-estimating the healthcare and support that they need. The difficulty getting GP appointments was exacerbated by the fact that the more severely ill people were least able to attend a GP surgery, and thus least able to access healthcare.

Despite these problems, it was agreed that as the initial sickness certification had to be carried out by someone, an individual's GP was the best person for this purpose. The GP is the person with the best overall view and has access to all of the patient's medical records. A person's GP is preferable to an external healthcare professional who does not know the patient or have access to the patient's medical history. Other healthcare professionals working with a patient do not routinely have access to the full medical history and typically are even less readily available than a GP. For people with MH conditions, the GP's word should be taken as the most authoritative regarding their patients' ability to work in the immediate future.

The group was emphatic that this approach refers only to those in the early stages of becoming sick. They themselves had been severely ill for many years, and their inability to work should be clear, rendering repeated GP confirmation unnecessary.

Some people with mental illness do not present to their GP until it is severe. At these points, a complete sign-off by the GP would be appropriate and necessary. In crisis, it is not appropriate to be focusing on work straight away. It is better to sign the person off work for long enough that the person feels safe and supported, and has the space to work on their mental health, than to jeopardise their treatment and recovery or management process by insisting on a swift return to work.

Other people have more moderate conditions that will respond quickly to therapeutic intervention. In this regard, sick leave is a valid and useful therapeutic tool. GPs commonly use sick leave as a treatment for depression, for example (MacDonald, et al., 2012). As a one-off, no further intervention may be needed at this time in order to make work sustainable. However, if sick leave becomes a recurrent issue then it should be considered a signal that more thorough support is needed.

The government should be ensuring that there are enough GPs to meet the need of the population and that all GPs are trained in MH conditions. The current situation where people struggle to see a GP – and to see the same GP – when they need to should be remedied, and the access to crisis care needs to be improved.

Physical Health

The physical health group was made up of an ME/CFS group with whom I communicated by email, due to the severity of their illness. They were unable to commit to meeting at a particular time because they could not guarantee that they would be well enough to attend, even if they managed their energy expenditure over the previous days very carefully.

The ME/CFS group reported the same issues as the MH group with accessing GPs. There simply weren't enough GPs to go around. This was exacerbated by the fact that, as with mental health conditions, when they were most ill they were least able to get to a GP.

The group also reported that, as long-term sufferers, they tended not to be in frequent contact with any medical professionals. They had long since exhausted the different treatments and therapies available, and were now in a position of managing their condition in a largely unchanging manner. There was nothing to gain by visiting a medic who had nothing to offer in way of treatment.

As with people with long-term mental illness, the process of retaining sick leave could not follow the same potentially intensive approach as for the initial sick leave. However, for initial sick leave, it was agreed that GPs are best placed to determine the immediate need for time off work. Ongoing sick leave should receive greater attention and investment so that those who can improve their work capacity are able to do so; for people where improvement is unlikely - either because it is medically unlikely from the start or because treatment and therapy options have been exhausted - a long-term sickness benefit should be available.

Brain Injury

The brain injury group were in a similar position to the ME group - there was little to nothing the medical profession could do in terms of treatment or therapy. Management or rehabilitation advice from medics was rare; the group reported that the only support they got was from their local brain injury charity. However, as with many such bodies in the current political situation, the charity was significantly struggling for money to continue its work. The charity itself did not know of any other brain injury charities anywhere in the country. Consequently, most people with brain injury get no support in their daily lives, and have no-one to advocate for them.

What the brain injury group did have was a medical diagnosis and prognosis from a consultant. This, backed up if necessary by a GP sick note, was considered sufficient for immediate access to sickness benefits.

Learning disability

The learning disability group were happy for a GP sick note to provide the initial access to sickness benefits. They considered that in general if a person has a learning disability it would be recorded in their medical files held at their GP surgery, and a GP could use this as the basis for signing a sick note.

Visual Impairment

I spoke with a blind person and a couple of RNIB caseworkers who were able to share the needs and concerns of the people they worked with. They reported that blind people usually have a registration confirming that they are blind, and this should be adequate for entrance to sickness benefits, as it was under Incapacity Benefit. For

people who were in the process of getting registered, a GP sick note would be a suitable alternative.

Hearing Impairment

The Deaf people with whom I spoke wished to make it plain that they did not, in general, consider themselves disabled. Rather, they spoke a different language, British Sign Language (BSL). The difficulties they experience are caused by hearing people not using the same language as them. This was reflected in their experience of claiming ESA. They often struggled in the initial stages because GPs would not sign the necessary sick notes to claim ESA before the Work Capability Assessment, because they were not sick. Deaf people often had to enlist the support of specialised deaf welfare advisers to explain to their GPs why the medical certificate was needed.

Deaf people tend not to be 'registered' deaf in the way that a blind person can be registered blind. This made an automatic entrance to sickness benefit slightly harder to achieve. However, a standard NHS hearing test showing a suitable percentage of hearing loss could act as the medical confirmation of the need for sickness benefit.

Final recommendation

The current situation of obtaining a sick note from one's GP for sickness lasting more than seven days was well supported by the focus groups. GPs were considered to be the professionals with the most appropriate knowledge for determining the initial need for sick leave. Many people needing sick leave may have a condition (e.g. a virus or broken leg) from which they will naturally recover and return to work with time, and so need no further intervention than time to rest and recuperate. Others may need further support to resolve the issues that are causing the sick leave, whilst still others may be in a severe crisis from which it is not appropriate to discuss work at that time.

Waiting until a person has been off work for long enough to need a sick note may be too late for a genuine 'early intervention'. Far from Cameron's claim of a 'sick note culture', the evidence is that sickness presenteeism and leaveism are far more common than sickness absence, and this has knock-on effects for the health, wellbeing and productivity of the workforce (Ashby & Mahdon, 2010; Garrow, 2016; Hesketh & Cooper, 2014). People attend work when sick because of workload pressure, financial pressure and cultural pressure to not be seen as 'pulling a sickie' (Ashby & Mahdon, 2010). In contrast to Cameron's claim, the UK has not a sick note culture but a 'sick-work' culture in which people who should stay at home for rest and recuperation instead feel pressured into working whilst sick, despite the detrimental impact that this has on their health, wellbeing and productivity at work.

It is much harder to detect sickness presenteeism than sickness absence, yet sickness presenteeism is widespread and detrimental to both the employee and the employer. People who attend work whilst sick are more likely to have future sickness presenteeism and sickness absence, suggesting that the overall effect is that they prolong their illness unnecessarily (Ashby & Mahdon, 2010). People who work whilst sick generally work at a lower speed and quality, to the extent that sickness absence to allow recovery would have been preferable. Where the illness is an infectious disease, attending work can spread the illness to other employees. Where it is related to stress in the work-place, sickness presenteeism masks inappropriate employment practices and reduces the financial incentive for employers to look after their employees. For these and other reasons, sickness absence can be preferable to sickness presenteeism, and

should be encouraged by employers and the State, so that appropriate mitigating and remedial measures can be employed.

The journey to long-term sick leave can take as long as six years from the initial sickness absence (Bratsberg, et al., 2010), or longer if sickness presenteeism is included. When a person reaches the stage of presenting at their GP practice requesting a sick note, this should generally be considered not as the first indication of an illness but as part of a process that has been going on for some time. It should act as a prompt to explore whether the person's illness is a one-off (such as influenza or norovirus) or is part of an ongoing sickness (such as repeated minor infections, lower back pain or stress) that is likely to recur. An ongoing health problem should be explored so that contributing factors can be addressed alongside healthcare and recuperation.

Line managers must become much more savvy about identifying sickness presenteeism, so that employees can be given access to appropriate support much sooner in the sickness process. 'Early intervention' should refer to changes made by an employer that starts before a period of prolonged sick leave, ideally whilst people are still attending work whilst ill. Employees should be able to access thorough occupational therapy assessments and support even when they have not yet taken any sick leave. Occupational therapy service should be separate from the employer, to reduce conflict of interest, and OT recommendations should be enforceable so that employers cannot sideline their responsibility to their employees.

Therefore, we recommend the establishment of a comprehensive occupational therapy service (OTS) for people with sickness in the workplace. Employees should be able to access this directly whenever they are concerned that work may be having a detrimental impact on their health or their health may be negatively affecting their work. GPs should also be able to refer their patients to this service whenever they have reason to believe that their patient has a health problem that is unlikely to naturally resolve without relapse, and which is not currently so severe as to necessitate a complete break from work for therapeutic purposes. The service should be separate from the employer, so that employees can be confident of the impartiality of their support team and feel able to discuss problems that stem from the workplace. The OTS should be a face-to-face service, rather than telephone based, so that employees can develop a positive relationship with their caseworker more rapidly.

The initial sick leave should continue to be obtained from the GP, as per the current practice. GPs should have the option to refer their patients to an Occupational Therapy service when they think this may help their patients to make an earlier, healthy return to work.

Assessment criteria and the need for sickness benefit

Current situation

The current assessment for sickness benefit, the Work Capability Assessment, is one of the harshest in the developed world (Grover & Piggott, 2012). At the same time, the UK offers the least practical support to sick and disabled people, give recipients one of the lowest amounts of benefit and demand the highest level of activity in return for that benefit (Baumberg-Geiger, in press). The consequence is that many sick and disabled people who cannot work or who cannot work without extensive support are required to comply with the inappropriate and harmful requirements of JSA or the Work-Related Activity Group within ESA, whilst living on poverty-level benefits and not receiving the support they need.

The WCA has been criticised many times in many places over the years since its introduction in 2008. A summary of its failings includes:

- A medical/functional rather than holistic assessment;
 - Difficulty assessing mental health, fluctuating conditions and chronic incapacitating illness;
 - Inability of the points-based descriptors to assess the risk of work on an individual's health;
 - No clear evidence on 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)

People who have to apply for benefits are placed in a position of vulnerability before the State. The State has the power to award, deny or remove benefits. The applicant is dependent upon meeting criteria set by the state, which may or may not bear a relationship to the applicant's need and reason for need. Only by meeting those criteria can the applicant obtain the income they need to live; people who do not meet the criteria have to find alternative income sources, which they may not be able to do given their illness or disability.

When benefit criteria are too strict, people who are too sick to work can be assessed as fit for work despite a correct application of the criteria. ESA is one of, if not the, harshest sickness tests in the developed world (Grover & Piggott, 2012). People who are assessed as fit for work often have substantial health barriers that make work difficult or unviable for them (DWP, 2013). These people are left vulnerable to JSA sanctions, on top of a poverty-level income, and at risk of worsening health that will only drive them on to ESA at a later date when an earlier award could have helped them stabilise their health and remain closer to work (OECD, 2003; French & Song, 2012).

When criteria are badly or rigidly applied, people have to go to appeal to get the award they need. The majority of people in the focus groups had experienced multiple WCAs where the recommendation of the assessor, and decision of the decision maker, was that they were fit for work. This had been overturned at appeal, only to be again wrongly assessed as fit for work at their next assessment. People undergoing the WCA are therefore often aware through their own experience as well as the experience of others that they are at risk of being denied the support they need to live. This puts both financial and emotional strain upon them; financial, because JSA and, from April 2017, ESA WRAG are worth around £36/week less than ESA Support Group; and emotional, because of the dual effect of being essentially assessed as lying and/or malingering and the effort and distress involved in recounting difficulties (again) and countering false assessments for the appeal process.

The WCA bears no apparent relation to capacity for work as measured by employability, likelihood of getting work and the ability to sustain work in the open labour market. It ignores key factors including skills and experience, the burden of

medical appointments, the impact of pain and fatigue, and the conflict with other responsibilities such as caring for dependent children. Furthermore, it ignores the needs of employers for a workforce that is reliable in both attendance and productivity.

Salway et al. (2007), even before ESA was brought in, reported that,

“There is also a need to increase the appropriateness of assessments of ‘fitness for work’. Current approaches fail to recognise employability as a contingent and dynamic process, dependent not only on the condition, but also on the other characteristics/skills of the potential employee and the labour market options available. The continuing use of capacity for (any) work as a yardstick for assessing benefit entitlement is overly narrow, potentially stigmatising and unfair to those who, much as they would like work, fail to get it. For those with long-term health conditions, insufficient consideration to their experiences of pain, fatigue and the burden of hospital appointments may make fitness-for-work assessments unreasonable...

“Our study findings therefore illustrate the need for the welfare reform agenda to address the question of potential inability of those deemed ‘capable’ of work to actually find a job (or a stable job), and consider what levels of support might be appropriate in such circumstances – rather than assuming the current overwhelmingly punitive stance.”

Other countries

In many countries the assessment of capacity for work is more of a process than a single event. In Australia, for example, sick or disabled people meet with an adviser several times over the course of three months, described as a “dynamic process with information collected over three months or so” (Nevile & Lohmann, 2011). In Iceland, a Master’s student recommended a programme of continuous evaluation, activation and treatment, organised according to the individual’s needs (Konráðsdóttir, 2011). The initial sick leave system in the Netherlands involves seeing doctors assigned to a particular industry, and these doctors continue to meet with the sick or disabled person over a period of weeks whilst they discuss the person’s capacity for work and measures to return to work (Meershoek, 2012).

A ‘procedural’ approach is typical of Germany and the Nordic countries. In these, there tend not to be any explicit decision rules, such as occur in the UK assessments for ESA and PIP, although there may still be detailed assessment forms (Mabbett, 2002). These forms are used to identify possible jobs or, more often, any training and assistive requirements, rather than to determine benefit receipt. Procedural systems necessarily rely upon “a high level of individual judgement and discretion” on the part of the assessor, and “may involve negotiation with the person over an appropriate rehabilitation plan” (Mabbett, 2002). In general, rehabilitation plans are used for up to two years and, if reemployment is not possible at the end of those two years, the person is transferred to a sickness pension. Thus, these countries identify through practice rather than proxy whether or not a person has sufficient capacity to work. Such high-discretion approaches are generally held in higher favour by sick and disabled people than the low-discretion, pigeon-holed approach of the UK system (Mabbett, 2002).

The UK is unusual in not attempting to show the link between its sickness benefit assessment and the capacity for work. The Netherlands, which compares individuals to a list of 28 types of action, still explicitly compares these to the actions required in specific jobs. The UK does not include information such as work pattern (e.g. whether a person can work predictably; or can work nights, shifts etc.) or a person’s skill

and experience base, all of which are included in the Netherlands' assessments. Even Ireland, which has a similar list of activities to the UK, has an additional work capacity assessment which is "more open and discretionary" (Mabbett, 2002). Most countries in Western Europe make some reference to actual jobs when considering whether or not a person has reasonable capacity for work.

Initial recommendation

The initial recommendation was that the criteria of fitness for work should be based on the following:

- The decision of capacity for work should include labour market competitiveness.
- 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.
- 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.
- A decision of fit for work is made if the assessor and the claimant can identify three jobs that the claimant can do without support.
- An assessment of not-yet fit for work is made if a claimant needs particular forms of support in order to be able to work. Support includes but is not limited to retraining, job broker-ship, technological or physical adaptations and ongoing personal support. The claimant is considered unfit for work unless and until that support is provided.
- An assessment of unfit for work is made if there is no work the claimant could feasibly do even with support. This includes but is not limited to people who can only work a small number of hours or who can only work irregularly and/or at unpredictable times.

Mental Health

In the MH focus group, it quickly became apparent that this initial suggestion was not appropriate for these people. The focus group told me that they were not in good-enough circumstances to undergo more assessments. Their MH conditions meant that at that time they did not have the capacity to manage their health well whilst also trying to navigate the benefit system and attend annual or biennial reassessments. This had been exacerbated and prolonged by the failure of the State to provide the necessary and appropriate healthcare and support services over multiple years. They were not ready for more assessments, let alone to consider or move towards work.

The WCA is poorly designed and the MH focus group participants reported that they struggled to convey what it was that kept them from work when completing the ESA50 form or at face-to-face interview. Most of the participants had had multiple cycles of assessment, appeal and reassessment. The criteria for ESA for people with mental health conditions are so tough that only people with very severe conditions can access it. People currently in ESA for mental health reasons can therefore reasonably be concluded to have severe and enduring mental health problems that render them currently and for the foreseeable future unable to work. The group therefore concluded

that people already on ESA due to MH conditions are currently too sick to work and are likely to be so for a period of years; therefore, no further assessment is appropriate or necessary. These people should be automatically transferred to a stable, secure benefit without conditions or reassessment.

For people in the early stages of a mental illness, it was agreed that it could be beneficial to have a comprehensive assessment of what support services should be put in place. This was referred to as a 'hub' where a range of medical professionals would meet the person and assess what support was needed; for example, counsellors, occupational therapists and community mental health workers. The purpose of this hub would be to provide the medical support and healthcare that is needed, and to additionally provide an assessment of what support would be needed in order to enable a person to work. The assessment would consider the impact of work on home life and social participation, and vice versa. The goal would be to improve health and well-being; in some cases, work or specific jobs/employers may not be compatible with this.

People who needed a brief time off work, for therapeutic purposes, would not need to be referred to this comprehensive service, as they might reasonably be expected to return to work as normal after some weeks off. The GP should have discretion to give people this time off, and only refer to a comprehensive hub if it became apparent that time off was not itself proving sufficient to enable a sustained improvement in mental health and a sustainable return to work.

The mental health focus group was concerned for people with a severe illness who could be harmed by the stress of an assessment that is related to capability and capacity for work, and which required meeting multiple professionals and/or engaging in detailed conversations about their current situation. Therefore, we concluded that GPs should have the option of waiving an additional assessment for people who were at risk of harm and who were clearly unable at that time to work or engage in work-related support.

For these latter two groups, GPs will continue to provide sick notes confirming the medical need to refrain from work up until it becomes appropriate for the person either to return to work, or to attend an assessment of what support should be put in place for them.

Physical Health

The people with chronic physical illness with whom I spoke were emphatic that they were not able to undergo further assessments of capacity for work, let alone move towards or into work. The punishing system of assessment, reassessment, appeal and sanctions were preventing these people from managing their health well, and causing their health to worsen. The associated stress and financial poverty meant they suffered the double blow of chronic illness and social exclusion, exacerbated by stress, distress and a government message that they were at best worthless and at worst criminal.

The focus group concluded that people on ESA because of a chronic illness should be on an equivalent to ESA Support Group, without the reassessments. These are people who, by the nature of their illness, are unlikely to receive any good from attempts to get them into work and may suffer significant harm. The WCA means that these people have already been assessed as too unwell to be able to work, or for it to be reasonable to ask them to work. There is therefore no new need for an assessment, even under an appropriate assessment system, especially as the nature of the WCA is that sick people are far more likely to be inappropriately assessed as fit for work than inappropriately assessed as unfit for work. Indeed, there is no evidence of sick people on

ESA generally being capable of work (bar recovery), and substantial evidence of sick people on JSA or ESA WRAG being incapable of work.

The current situation of repeated reassessments for the long-term sick is actually perpetuating their illness.

Brain Injury

The people with brain injury to whom I spoke knew very well that they were unable to work. They already worked “a helluva lot” just getting through every day. Many of them had, through their support group, learnt compensation mechanisms to cope with their memory loss and cognitive deficit, but the compensations themselves were fatiguing.

For example, they had been taught to keep all of their important belongings in one place all of the time, but forgetting to do so was easy; one reported a two-hour panic when he could not find his wallet after forgetting to place it in his ‘hub’. They had diaries, calendars and notebooks that were kept in their ‘hub’, with additional

I’m totally dependent on my notepad; I need it to survive. My life revolves around my notepad.

notebooks that they carried everywhere in order to record every event and conversation. Without them, they would leave a conversation with no recollection of anything that was said either by themselves or by others.

Some no longer used debit or credit cards, because they could not trust themselves to take the card from an ATM after use. Others kept their cards, but could only safely use an ATM by dint of strong concentration and repetition of the phrase ‘card-cash-stash’ to make sure they did not leave anything behind.

They used checklists and flow-charts to get them through daily tasks such as making a bed or a cup of tea. Without them, they were unable to carry out an activity that involved a sequence of actions. Being taught an activity or task on one day did not mean that they could perform the same thing the next day; they would need to be shown again. They relied heavily on other people helping them, usually charity staff or parents, and were unable to live independently or carry out even the most basic of actions.

My mum’s always in the background. It’s demoralising.

Work could not be performed under pressure, because they were unable to work at the speed expected of unskilled or low skilled employees, and nor could they sustain work for the hours expected. Support group members reported having to leave jobs when targets for speed or efficiency were increased, because the higher level required was not possible for them. Where they tried to continue working, they struggled with morale as performance-based bonuses could not be achieved, and when bonuses were for teams rather than individuals then the slower speed of those with brain injuries held back the whole team.

Overall, therefore, the experience of the brain injury focus group was that they were not capable of work in the open labour market. What work they could do was severely restricted in hours, and even then they could not keep up with the speed requirements of the modern workplace, or carry out more than the simplest of tasks without supervision or guidance.

They struggled to claim benefits. Initial telephone conversations were impossible to follow, because they could not retain a memory of what had been said or concentrate on what was being said. They found that their assessors had no relevant knowledge or experience of the problems caused by a brain injury, and were therefore unable to make an accurate assessment. They reported that the assessors regularly paid no attention to the ESA50 form or to evidence submitted by the claimant's doctors. Many of the participants in the brain injury group had had yearly ESA assessments and at each one were assessed as fit for work, with no change to the decision at mandatory reconsideration, and then awarded ESA within a few minutes at the Tribunal hearing – only for the process to start again a short time later.

My assessor was very good with words, to get me to say what she wanted me to say. She got me in knots.

[Telephone conversation is] just a deep black hole. I can't remember what I did say or should have said. I get up lower [in mood].

The WCA is simply incapable of assessing the capabilities of a person with brain injury as the questions it asks are irrelevant. Nothing is asked that establishes the nature of the problems experienced by people with brain injury or the impact on capability for work. Its simplistic test of whether or not a person can repeat three words or spell a five-letter word backwards bears no relation to the memory impairment and cognitive deficit caused by brain injury. Whether or not a person can set an alarm clock is irrelevant to whether or not a person can learn a new task and still know how to do it the next day. One lady, for example, reported how she had had six weeks of 're-enablement' trying to teach her how to make a bed – and she still couldn't do it. Asking only about alarm clocks meant that where, for whatever reason, the memory of how to do that was retained, it was taken as evidence of good memory and ability to learn even when other similarly simple, routine tasks could not be performed.

I can't even fill in a form for a bus pass. It's been rejected three times.

Many of the group members felt strongly that their appearance was against them. They reported being assessed as fit for work because they were dressed, clean shaven and not rocking on their chair. Some were highly articulate and this had also been taken as evidence of cognitive capability, despite the fact that their brain injury impacted memory and concentration, not speech; one reported that whilst she spoke very well, six weeks of one-on-one teaching had not succeeded in enabling her to make her own bed. Because managing their condition was so exhausting, looking alright during a one-off assessment bore no relation to the actual capacity for work. The brain injury group

reported that an hour's conversation as in a WCA would render them unable to anything else for the rest of the day, and possibly for several days to come.

So far today I've been okay, but I might collapse this afternoon, and then tomorrow I might wake up shitty with everything tits up from start to finish.

The group struggled to maintain positive mental health. They were all very aware of the difficulties they experienced and the many reasons why they could not work. Many had been highly successful prior to their brain injury, but were now dependent upon micromanagement from their parents. They felt frustrated and depressed by the absence of hope for the future. They did not want to be dependent upon others for either financial or practical support.

I'm not a happy bunny, so friggin' worried. Every time the postman comes, every brown envelope, I have an absolute meltdown.

Why should I have the humiliation of going to [Tribunal] court just to get support for basic needs? I'm treated like a criminal; it's not on.

The group strongly agreed that an assessor should have good knowledge of the impacts of living with a brain injury. They felt that in general their GPs did not have enough knowledge. None of them saw consultants for their brain injury, because there was no medical help that could be provided and therefore nothing to be gained. For those with multiple health conditions, it was difficult to coordinate the advice they received from each consultant, and the NHS did not provide any overarching clinicians to help people with multiple conditions. This meant that there were no consultants who were able to speak comprehensively about the health and work capacity of people with brain injury.

Learning disability

The Learning Disabilities focus group was concerned that neither the social security system nor the open labour market were accessible to them. The social security system was for them opaque and tortuous, with an emphasis on denying benefits rather than on providing support and care. They experienced no interest from employment support staff in understanding individuals' needs or enabling them to do what they can. They struggled to understand the benefits they received including financial eligibility and the conditions expected of them, and in the words of the Work and Pensions Committee are "set up to fail" (Work and Pensions Committee, 2015). JobCentre and Work Programme staff appeared unable to tailor conditionality appropriately, and consequently learning disabled people were particularly vulnerable to sanctions; they are both more likely to be sanctioned and less likely to be able to deal with a sanction (Oakley, 2014; Work and Pensions Committee, 2015).

Their experience of the open labour market was one of repeated bullying that eventually left them unable to work at all. Members of public did not always speak comprehensibly, and if asked to clarify would often repeat the same words rather than find a different phrase. They would mock and ridicule learning disabled people, or openly resent the accommodations a learning disabled colleague needed. This left the people in the learning disabled focus group feeling belittled and dehumanised, and caused them significant anxiety problems. They explained that it couldn't be assumed that they would always sleep well, attend work or appointments on time or be fully functioning; therefore, 9-5 Monday-Friday jobs were inappropriate and inaccessible. However, they spoke warmly of supported employment (Remploy) and third sector organisations such as the church that was supporting them.

The group reported that what would help them would be to be exempt from a test for sickness benefit by using the GP's medical records to confirm the presence of a learning disability. This would remove the stress caused by the unnecessary WCA. They should be placed in the ESA SG because the conditions of JSA and ESA WRAG caused only trouble and hassle that removed their ability to participate in society in some way. In the Support Group they should still have access to support if they want it. In particular, they wanted support to access voluntary work, and they wanted the provision of supported employment whether through Remploy or, as one individual suggested, group jobs for learning disabled people supplied by the council.

Visual Impairment

I met with two RNIB caseworkers who helped visually impaired people with their benefit claims, including appeals and managing JSA or ESA WRAG conditions. I also had email discussions with other blind people.

In the discussion with the RNIB caseworkers, it was reported that the current criteria for ESA are inappropriate for blind people. The assessment fails to give consideration to the impact that visual impairment has on the overall speed of life; many tasks take longer to complete, and this necessarily leaves less time available for work. Many blind people struggle to get into the Support Group because its design means that there are no criteria which they fit, yet the conditions of ESA WRAG are inappropriate. What they needed was not mandation to look or prepare for work, but someone to create a suitable job and provide the necessary technological and physical assistance for them to undertake it. The WCA did not attempt to assess this.

I know my limitations and know I can never be as productive as a sighted person. I accept that and so should others. People seem to think having a job is it. No thought to how to get there, navigate even the door, refreshments, speaking with people, just everything.

Blind people share common difficulties with one another in regard to their lives at home, in the public environment and at work. They therefore share common support needs. It would be reasonable to assess all blind people as unable to compete without support in the open labour market, and unable to comply with the JSA requirements. Therefore, they should all have access to a benefit that does not carry conditions or sanctions, and that comes with a commitment from the government to provide the necessary support. This is likely to include a job broker who can liaise with local employers to find or create jobs for blind people. The government should be committed to providing transport for

all blind people to get to and from work. It should also be required to provide any necessary assistive technology or other appropriate aids and ensure that these are in place before a person is due to start work.

Hearing Impairment

Deaf people found the process of claiming benefits to be inaccessible and largely unrelated to their needs. Many of the questions on claim forms and at face-to-face interviews are irrelevant to the problems society has created for people with hearing impairment. Those questions that are relevant, typically a single question on aural/visual communication, are written in English using English vocabulary and grammar. For a deaf person, English is not their language; BSL is. To read English they have to translate it into their own language, and this is not easy for someone who is not fluent in English. The language used in benefit application claims is too complex for deaf people to accurately interpret.

Overall, the deaf people I met felt that the biggest issues were the mismatch between benefit criteria and being able to get a job, and the lack of provision of BSL interpreters at all layers of society. The criteria for claiming ESA simply aren't related to being able to get a job or being able to work. Yet deaf people all experience difficulties with getting work and need certain support to maintain work, and these difficulties and needs are largely similar across all deaf people. It is therefore appropriate to assess deaf people generally as needing a safe, secure benefit whilst also being given the BSL interpreters and other support they need to get and maintain work.

Unlike blind people, deaf people tend not to be registered as having a sensory impairment, so it would be less easy to have an automatic qualification based on deafness. The deaf people with whom I spoke felt that appropriately specialised professionals would be able to assess the extent to which a deaf person is able to work and look for work. Generic professionals would not be suitable for such a role because it is not possible to have the in-depth knowledge of every condition or impairment that is necessary for a valid assessment; this is, after all, why the medical profession is not solely made up of GPs and general surgeons. A specialist professional can make an informed and valid decision on whether a person can manage the conditionality and open labour market of JSA, or needs a benefit with guaranteed access to BSL interpreters and other support measures before applying some, if any, conditionality. Additionally, access to a new sickness benefit could be automatic for people with a given percentage of hearing loss, as confirmed by an NHS hearing test.

Other respondents

Other respondents strongly agreed that the ability to work must include the impact of things like not being able to work at as fast a pace, or needing more and longer rest breaks, or being able only to work in small amounts at random times. These strongly impact an individual's productivity and thereby also his or her employability in the open labour market. People who cannot keep pace with their healthy, able-bodied colleagues are not going to be recruited and retained in a market place where the goal is profit. The focus should be on the barriers that sick and disabled people face, using the social model of disability, rather than locating the 'problem' in sick or disabled people themselves.

They also agreed that a decision of Fit For Work needs to be linked directly to employability and the job market by identifying jobs that the individual can compete for and sustain at an equal level to healthy, able-bodied workers. One respondent suggested that the availability of jobs should be included in this; if a person could do a

job, but no such job exists within the local area, that person is practically not going to be able to work. Nothing is gained by adding jobseeker's level penury and conditionality to a person who already has chronic illness or disability.

Assessment should be based on a discussion between the assessor and the claimant focused on what the claimant can do and what support would be needed to do it. The assessment should assess possible jobs before finding someone fit for work. There should never be any trick questions and spurious inferences.

The criterion for Fit For Work, of being able to work in three or more jobs in the open labour market, was seen as valid, practicable and appropriate. Whether a person might be able to work in the future was something that could only be discovered through a working relationship between the sick or disabled person and their support worker. In a system that recognised that sick and disabled people want to work and would take advantage of efficacious support, this would naturally return the result that those who can work get and sustain work, whilst people who struggle to work wouldn't be able to sustain work or engagement with the support worker.

Respondents indicated that in practice, the GP triage system would allow GPs to filter out those obviously able to work (bar cases where the GP wasn't sufficiently confident) and those who clearly couldn't work. The majority that reach the assessment would therefore be people who would fit a criterion of 'may be able to work with support (in the future)'. It should therefore not be considered a failure if significant proportions of claimants are assessed as unable to work in the open labour market without support, i.e. as not fit for work. In practice, providing adequate employment support would protect against any risk of long-term worklessness amongst those who might be able to work.

It seems to me that much of the difficulty with devising adequate criteria and making accurate decisions would disappear if claimants were treated as active participants in the assessment process and the employment support provided were truly supportive.

Final recommendation

Similar issues came up across the different groups although they were typically phrased in different ways. All the groups felt that the conditions of Jobseeker's Allowance or ESA WRAG were inappropriate for them, largely because they could not meet conditions either consistently or at all. The more static disabilities - blind, deaf or learning disabled - were in favour of supported employment; the chronic illnesses - ME, MH or brain injury - reported that they could not work at all or only in such small amounts as to be effectively unable to work. They all reported that their conditions were not going to change from their current state or were very unlikely to improve.

Those with a disability but who are not ill need ongoing support both in and out of work, at home and in the wider environment. Within an impairment type, people with that impairment share a minimum set of barriers and support needs, which are sufficient to merit an award of a long-term sickness benefit combined with employment support. An automatic entitlement to sickness benefit would therefore be appropriate

for at least the three disabilities (blind, deaf, learning disabled) discussed in this report, based upon medical confirmation as registered blind, a high percentage deaf, or recorded as learning disabled on GP medical records. Other conditions may also merit automatic access to sickness benefit, such as cancer (during treatment and for an initial recovery period) and severe autism spectrum disorders. We therefore recommend that the assessment for disabled people be based upon automatic 'passes' to sickness benefit where a specified level of impairment has been met.

When it comes to assessing and supporting people with illness, it is important to first understand the nature of sickness in the workforce and the ways in which this manifests. Sick leave can be considered as a spectrum from one-off illness or injury, to recurrent or long-term sick leave associated with ongoing problems; it also occurs in a range of severities, from mild illness or injury that doesn't require sick leave, to severe illness or injury that, for as long as it lasts, requires complete sick leave. A one-off illness or injury is unlikely to need any employment support as it would naturally resolve with the patient returning to their previous health and capacity for work once healed. Recurrent sick leave and/or long-term sickness presenteeism however indicates an ongoing problem that is not currently being managed well; if a person repeatedly needs a break from work, it suggests that there is something about work in combination with their health and daily lives that means that they cannot sustain work at that level. These people need support; health issues must be identified and treated, and activity – whether at work, at home or elsewhere – needs to be brought into proper management.

For people in the initial stages of sickness or disability, a procedural approach would be the most appropriate form of assessment. This is what was suggested in our Part 2 report, and which the focus groups I spoke with confirmed as appropriate for people who are still sufficiently 'early on' to be likely to be able to return to work if given help. It is also internationally recognised as the best approach for assessing the capacity for work of a sick or disabled person (Mabbett, 2002; Baumberg-Geiger, in press). A procedural approach is one which establishes a person's capacity for work by discussing the support that an individual needs in order to work and the type of work that is possible, and then trials whether that support is sufficient. A form may be used to help gather information, as this tends to increase the assessor's understanding of the depth of disability that is experienced (Spanjer, et al., 2010).

Because procedural assessments are not formulaic, they must be conducted by a professional with suitable training. Medical professionals do not have the expertise necessary to relate a person's illness or disability to their ability to work (Clifton, 2006). A patient's doctor can advise on whether a break from work would be therapeutic, a person cannot work (for example, capacity for activity overall is limited) or a person is no longer ill. But beyond that, GPs recognise that they cannot comment on the detail of what work a person can do. A different skilled profession is needed – Occupational Therapy, or for mental health conditions a professional such as a Community Mental Health Team worker.

The initial stage, as in current practice and supported by both the original survey results and the focus groups, is the medical confirmation of an illness. This is covered by GP sick notes. For the procedural assessment, medical evidence should be sent to the Occupational Therapist who will carry out the assessment. This would include self-reporting from the individual of their illness(es) or disability, and the collection of evidence by the assessor from the individual's GP and, if indicated by the individual, other medical or social care professionals. A small number of respondents to the consultation wanted the individual to be responsible for collecting medical evidence, but the majority agreed that the financial and practical burden for this should fall upon the

assessor/DWP. GPs are under a heavy workload and financial pressure, so the DWP must ensure that the request for medical evidence is clear and as brief as possible, and that it is adequately paid for. There is a wider role for the government to improve funding to GPs, particularly in deprived areas, so that there are enough medical staff available to cover the demands placed upon GP services.

For people who have a job contract, the Occupational Therapist would carry out an assessment of what the person needs to support them to improve and maintain their health and well-being, including but not limited to changes at work. The OT should be able to 'prescribe' adjustments such as reduced hours, phased returns to work, changes to job role and paid disability leave; these prescriptions would be binding upon the employer, to ensure that employers do not evade their responsibility to their employees. Small businesses who would struggle with these prescriptions should be funded and supported by the government, so that employees of small businesses are not disadvantaged by the size of their employer. The OT may identify a need for healthcare, such as physiotherapy or counselling; for support at home, such as through social care, disability benefits and respite care; or for support in the wider environment, such as assistance to attend religious, community or social gatherings or to engage in sports, hobbies or voluntary work.

Each individual should have a case manager, who might be the original OT they saw but may also be a different professional depending upon their primary need. For example, a manual worker suffering from a long-term severe knee injury may want to have a physiotherapist as their case manager. The case manager's role is to help support, encourage and monitor progress of their clients as well as liaise with other people involved such as GPs, counsellors, physiotherapists and employers. These case managers should be clinical staff, possibly based within the NHS so that they can liaise with other health services. The OTS should provide access to physiotherapists and specialist physiotherapists, counsellors, support staff (including Community Mental Health workers), specialist nurses and occupational therapists. The employee should be able to choose the medical profession of the caseworker they see, so that they can see someone whose expertise is most closely aligned to their needs. The caseworker should have the option to refer the employee to other staff within the OTS as appropriate, and to also be able to liaise with primary and secondary care services in the wider NHS.

The Occupational Therapy Service for people without a job contract follows the same process. The difference is that for initial sick leave, an individual on leave from a job has an employer to whom changes can be recommended or required, and these interventions can be trialled until work becomes sustainable. In contrast, someone who does not have an employer is not in a position to trial different 'adjustments', and a prospective employer cannot be expected to take on an employee with an unknown capacity for work. The role of the OT in this situation therefore is to determine whether or not a person could work without support.

The purpose of the OT assessment is not to establish the medical nature of reduced or in- capacity for work – that is covered by the GP and self-reports, and a separate assessment can add nothing of value, based as it is upon one-off observations and interpretations of the individual's answers. The purpose of the OT assessment is to discuss with the individual what capacity they do have for work and what support would be needed. Through this discussion, an initial recommendation can be made of how much work the individual can carry out, what type of work, and what support is needed. This is similar to Scope's recommendation that the government replace the WCA with "a Distance from Work Assessment, focused on identifying an individual's barriers to work and referring to appropriate support" (Gulliford, 2015). In line with the social model, it should be recognised that some of these barriers lie outside of the individual, such as

the provision of support or access to education, and are therefore not in the individual's power to remedy. Barriers that lie within the individual, such as fatigue that reduces capacity for activity, are not amenable to remedy.

In the focus groups, we discussed the importance of a multi-disciplinary approach. It was felt that the assessment of capacity for work and support needs should take place in a 'comprehensive hub' where there was access to the forms of non-work support that is likely to be needed. This is particularly the case for healthcare, where support including counselling and physiotherapy should be available, but there should also be advice and support available for other matters such as finances, relationship support and anger management.

For people with disabilities, as discussed above, the entrance to sickness benefit is in recognition of their need for support to find work and support in the workplace. For people with chronic illness, the need for sickness benefit is because they can't reasonably be expected to work, or might be able to work but the possibility of work needs to be explored in a very safe environment. To be found fit for work, therefore, the OT would have to be able to show that the sick or disabled person is capable of work in the open labour market without support. In the consultation responses, it was felt that a person capable of consistent part-time work without support – currently defined as 16 hours or more per week – should be considered fit for work. Previously this would have been topped up by Working Tax Credit. However, under Universal Credit, because Universal Credit also includes the expectation to increase hours and wages, a person in part-time work because of health reasons may need to have ongoing contact with an Occupational Therapist to safeguard them from the requirement to seek more hours than they are capable of doing.

A person would be referred to the OTS by their GP. It could be part of the sicknote that the GP records whether or not a person has been referred and if not, why not, in order to monitor the referral practices of GPs. The referral should be the default position, perhaps becoming compulsory after four weeks' sick leave, with waivers for patients that clearly do not need support beyond the natural resolving of a short-term condition (for example, influenza or a broken limb) and for those patients who are so severely ill or disabled that it would be harmful or simply unnecessary to have an assessment at this time. To prevent abuse of these waivers, it may be appropriate for the patient and the doctor to submit evidence to the OTS about why a waiver is appropriate, so that the OTS can decide. If the OTS considers a waiver is not appropriate, they should talk to the claimant's GP before making a decision. This would reflect and simplify the current system of an ESA50 (which typically does not ask the questions felt to be appropriate by the benefit claimant) and paper-based WCA decisions.

We therefore recommend the following:

- Automatic access to sickness benefit for people registered as blind, above a certain threshold of hearing loss, or recorded as learning disabled on their GP medical records. This is in recognition of:
 - Their need for employment support;
 - The longer time they are likely to be on benefits compared to jobseekers; and
 - The difficulty they experience complying with conditionality regimes.
- Automatic access to sickness benefits for people with other disabilities as appropriate;
- The transfer of current ESA recipients onto the new sickness benefit without reassessment;

- Assessment by Occupational Therapists for new claimants to sickness benefit, covering what they can do and what support they need in order to do it. Assessment of fit for work is based upon being able to work immediately in the open labour market without support;
- Individuals are considered suitable for the new sickness benefit when they:
 - Due to illness or disability, cannot comply with Jobseeker's Allowance conditionality;
 - Due to illness or disability, need support to prepare for, find and/or stay in work of at least sixteen hours a week;
 - Due to illness or disability, are unable to consistently work sixteen hours a week;
- Sickness benefit recipients are supported to engage in appropriate back-to-work support, including volunteering and retraining, without losing their benefit.

Assessor and Assessment Process

Current situation

Currently, medical personnel (usually nurses or physiotherapists, but sometimes doctors) make a recommendation on whether or not a person is fit for work according to the WCA criteria. The recommendation is made based upon the evidence submitted in the ESA50 form (completed by the claimant), any other submitted evidence such as medical evidence, and the face-to-face discussion with the assessor.

The recommendation is sent to the DWP where it is received by DWP Decision Makers. These people are not medically trained, and nor are they legally trained. Their role is to review the evidence and recommendations as submitted by the assessor, and decide which benefit group to place the claimant in. In the majority of cases, the decision is the same as the recommendation made by the assessor. Decision Makers have been criticised for 'rubber stamping' the assessor's decision, i.e. by not changing the decision from the recommended one. At the same time, when Decision Makers make a different decision from that recommended by the assessor, it raises questions regarding the Decision Maker's competence to reach a different opinion when they have not seen and spoken to the individual concerned, and do not have any relevant medical or vocational training. There are therefore concerns regarding the added value of a DWP Decision Maker, particularly relative to the additional potential for human error created by adding in another person.

Decision making is not relevant to people with illnesses or disabilities that entitle them to sickness benefit without assessment.

Initial recommendation

The initial recommendation was that GPs refer people as appropriate to an assessment of their support needs, i.e. what support would enable these people to work and obtain work. It was recommended that this be someone like an Occupational Therapist (for physical health conditions) or a Community Mental Health Worker (for mental health conditions). The GP would have a triage role, as some people would benefit from time off without an investigation of work capacity whilst others will have a naturally time-limited condition and will return to work in full health without intervention. These people would not benefit from intervention, so would not need to be referred to an assessment of their support needs.

There was strong approval in the survey for the assessor to be an individual's GP. However, this is not a role which GPs wish to take on. This is partly because of the damage it could do to their relationship with their patient if they considered the patient to be capable of work, and partly because they do not consider they have the appropriate professional expertise to assess an individual's capacity for work. Therefore, the survey included Occupational Therapy as a suitable profession for the assessment of capacity for work and support needs. Occupational Therapists "assess the complex interplay between the person's skills and limitations, the social and physical environment and the demands of the task, in order to offer individualised intervention plans that can enable people to reach their goals" (COT, 2016).

Because other countries have several meetings between an assessor and the sick or disabled person before a benefit decision is made, we included this option in the survey questions. The purpose of this is to mitigate the problems caused by having a single, 'snapshot' meeting and to give the individual time to add extra information. This could include the impact of the first meeting on the individual's health and wellbeing. 69% of respondents thought that this could be a good idea, compared to 20% who thought it could be a bad idea. We therefore recommended that there be several meetings before a decision is made.

Other recommendations based on the original questionnaire were:

- Medical evidence is collected before the assessment (95% in favour, 1.5% against);
- Opportunity to comment on the assessor's initial report and decision (95% in favour, 1% against);
- The assessment explores ways to help the individual into work before making a decision (58.5% in favour, 22.3% against);
- The assessor has to identify jobs that the individual could do if the individual is to be found fit for work (71% in favour, 14% against); and
- The assessor is the same person who works with the individual to support him or her to work (53% in favour, 19% against).

Mental Health

As with using GPs for the initial gateway to sickness benefits, the mental health group were concerned about the wider role of GPs in the sickness benefit system. They were happy to have GPs sign the initial sick notes, but wanted the sickness benefit system to be separate from healthcare (because they considered linking health and work to be inappropriate and dangerous).

Some of the participants indicated that they thought that the assessor and the decision maker should be separate people, although they did not give a reason for this.

The mental health focus group was concerned about the impact of having more than one meeting with an assessor. They felt that this would be too difficult for people with severe mental health conditions.

The group strongly agreed that medical evidence should be collected by the assessor/DWP, and not by the individual. This reflects current recommendations (albeit not acted upon by the DWP) that medical evidence should always be sought by the DWP when a claimant has a mental health condition (Hassell, 2013; Pring, 2016).

Physical Health

The physical health group was also concerned that they were not well enough to have multiple meetings with an assessor.

Brain Injury

The brain injury group struggled with meetings because of their difficulties with remembering what has been said so far in a conversation, and recalling what was said in a conversation after it finished. Multiple meetings might not add any value for them, because they would not remember what they had or had not said, and therefore would not know what needed bringing up at the next meeting. They relied heavily on the support of other people in conversations, where a third person could remind them of what has already been said and prompt them as to what has not yet been said.

Other respondents

Other respondents were also concerned about the suggestion of having more than one meeting with an assessor. One respondent pointed out that it could delay payments and add to the expense of the assessment process. The same respondent strongly felt that the assessor should never be the decision maker. Others, however, thought that the number of meetings should depend on each individual and not be determined in advance. There was also support from some respondents for the assessor to also be the decision maker.

Respondents had conflicting opinions over who should carry out the assessment. Some considered that the assessor should be an individual's GP and that no other input is needed. Others felt that there is a strong need for an independent assessor, both because of GP's concern regarding their own professional expertise and the potential damage to the GP/patient relationship. This fits with the mental health focus group, who considered that the healthcare system should have no role in requiring sick people to work.

Respondents agreed that the DWP or assessor should be responsible for collecting medical evidence. This reflects best practice as recommended by coroners and judges, and ensures that sick and disabled people do not effectively end up having to pay to apply for sickness benefit, or are disadvantaged by lack of finance or practical support.

The professionals undertaking the assessments must have an adequate level of training and professional ability. This follows the law set by Judge Hale when she ruled that a physiotherapist cannot assess the work capacity of a person with mental illness; a physiotherapist in that situation lacks the necessary professional expertise. Needing to rely upon a tick-box or points-based system to reach a judgment indicates a lack of the necessary expertise. Doctors do not diagnose their patients by filling out flow-charts and scoring systems. Medicine is described as both an art and a science; the assessment of capacity for work requires a similar level of professional expertise and discretion.

A collective disabled-led organisations response suggested that the assessment should be largely based upon self-report, with verification by appropriate health professionals. There should still be a discussion with the individual before a final decision is made. There should also be support for sick and disabled people made available through local user-led deaf and disabled people's organisations.

Final Recommendation

All of the chronic illness groups approved of the idea of a 'comprehensive hub' for people in the early stages of what may become chronic illness. At this hub, people with chronic illness get an assessment of what support they need (because of their illness) in order for them to be capable of work. If support is needed before a person is able to work, it is provided at that hub (if it is not needed, the person is placed on Jobseeker's Allowance). Discussing what support is needed and coming to an accurate first-time decision might require more than one meeting for some people, but for other people multiple meetings might be detrimental. A compromise solution might be to have a default of three meetings, spaced a month apart, unless either the individual requests no further meetings for health reasons or the assessor determines that the individual qualifies for sickness benefit without further meetings.

The individual should see and have the opportunity to respond to the assessor's initial decision and reasoning, which would then go back to the assessor before a formal decision is made. If the individual disagrees with the formal decision, there would be direct recourse to appeal at the First Tier Tribunal, where the Tribunal panel consists of a Judge, a Doctor and a person with experience of chronic illness or disability. The current system of Mandatory Reconsideration would not occur under the new system.

Reassessment

Current situation

ESA currently has a built-in system of reassessment. As part of the Work Capability Assessment, the assessor will make a recommendation of when the sick or disabled person should be called back for a new assessment. These 'prognosis dates' can be from three months to two years, or 'in the longer term'. The assessor making this recommendation is not considered to be giving a medical prognosis (this would not be legally ethical) nor an indicator of when the claimant may be fit for work; it is solely an indicator of when to assess someone again. This is based on "when there would be reason to expect a change in the claimant's functional abilities" (Work and Pensions Committee, 2014).

There has been substantial discomfort regarding the frequency of ESA reassessments (Work and Pensions Committee, 2014). It is widely felt that sick and disabled people are typically re-assessed too often given the long-term nature of their illness or disability. This is particularly the case for people with progressive or terminal conditions, although it also applies to people with incurable illness. Professor Paul Gregg, one of the original contributors to ESA, considered that sick and disabled people would typically need at least two years on sickness benefit, rendering re-assessments within that time useless and inappropriate.

Frequent re-assessments overloaded the previous provider, Atos, with the consequence that the DWP had to temporarily suspend all reassessments from January 2014 (Benefits and Work, 2014), a decision that remained in place for almost two years (Rightsnet, 2015). The DWP has not been forthcoming about current prognosis dates and reassessments, leaving many people unsure of how long their benefit will last and consequently living in fear of receiving a 'brown envelope' summoning them for a new assessment.

The UK is unusual in having periodic reassessments of sick and disabled people. Other countries, particularly the non-Anglophone countries, typically have a period of rehabilitation and support, during which measures to support a sick or disabled person

into work are trialled. If these are not successful, then the person is often transferred to a sickness pension, particularly when the recipient is an older adult. There is thus no need for reassessment, because the fact that the person has not moved into work despite the provision of support is itself an indicator that the person should not be transferred to an unemployment benefit.

Initial recommendation

We recommended that, as part of a new sickness benefit with a new assessment and support process, reassessments do not occur other than as a very 'light-touch' confirmation that people with severe and enduring illnesses are not yet ready to be supported to find and sustain work. In the proposed system, people who have some capability for work would be in touch with an Occupational Therapist or caseworker, whose role would be to ensure that all necessary support is in place, and to assist the individual to find and maintain a job. These people would not need reassessing because the OT would be aware of their health and disability. People who are too ill or disabled to be in regular touch with an OT or caseworker could have their ongoing illness or disability confirmed by their GP or other key medical professional.

Mental Health

The mental health focus group was very clear on the harm caused by the current system of assessments and reassessments. Both reassessments in general and WCAs in particular were stressful and damaging to mental health. People with severe and enduring mental health conditions are not able to focus on managing their illness when they are living with the stress of financial uncertainty. This is exacerbated by the receipt of a re-assessment letter and the stress of having to recount mental health difficulties under a system not designed to cope with mental illness and the past experience of being assessed as fit for work and then having to go to appeal to re-instate ESA.

Even with an appropriate assessment, assessments are stressful and can be detrimental. The group found it difficult and emotionally distressing to discuss their illness and its impact on their life. Having gone through an assessment once, further assessment was at best unhelpful and at worst actively harmful.

The NHS has never understood that mental illness can be life-long.

Physical Health

The physical health group reported that they were not able to take part in any system that involved repeated assessments of their illness and capacity for work. This was because they were too ill for repeated assessments to do anything other than take up precious energy and health, leaving them with worsened symptoms and reduced capacity for more important and helpful activities. Light reassessments, or check-ups, based on medical records would be more appropriate, with sickness pensions for people who are approaching retirement age and are very unlikely to see a recovery that would also result in them obtaining meaningful work.

The vast majority of ill people are chomping at the bit to recover and return to paid employment, will know when they're ready and will inform the DWP without prompting.

Brain Injury

The brain injury focus group reported that repeated assessments caused their mental health to deteriorate as a consequence of having to repeatedly go over their impairments, in the face of ignorance and disbelief. They described it as “psychologically very bad” for them to keep going through assessments, with a lot of anxiety and distress caused by the uncertainty of whether they would retain their benefit and income.

The situation of repeated reassessments for the long-term sick is actually perpetuating their illness and is thus, from a DWP cost perspective, counter-productive.

Their impairments did not change or go away between assessments, however many strategies they learnt. They still had the underlying brain injury, and given its intractable and unchanging nature, there was no reason to keep reassessing their capacity for work. It should be sufficient for an initial assessment to confirm that they could not work even part-time in the modern workplace, and for there to then be no further assessments.

Learning disability

The learning disability group reported that they struggled to understand benefit forms and the benefits system generally. They strongly felt that a different benefit system was needed. Their learning disability was not going to change, nor were they going to be able to navigate the system, and so reassessments served no useful purpose whilst risking causing them to lose their benefit due to misunderstanding or mistakes.

Visual Impairment

The people with whom I spoke considered that if the right assessment were carried out initially, and the right support offered, there would be no need for reassessment. In an appropriate system, people who could work but struggled to do so because of visual impairment would receive the support they needed until they were in suitable work. Automatic access to benefit on the basis of registered visual impairment, as discussed above and as has previously been used for Incapacity Benefit and Disability Living Allowance, would also remove the need for reassessment.

Hearing Impairment

The deaf focus group did not discuss repeat assessments specifically. However, they did report that the WCA was inappropriate for them, due to its poor consideration of the barriers caused by deafness in the workplace and a lack of relationship between its descriptors and the capacity to work. Where the initial assessment fails, repeat assessments using the same criteria and method are not going to work.

Final recommendation

Where there is an appropriate assessment and support system, there is no need for a process of reassessment. Those people with potential capacity to work would be in contact with a support worker who could confirm the ongoing presence of an illness or disability. People not in such contact would be people with an illness or disability that is

unlikely to improve and which is not amenable to support measures. For example, severe chronic fatigue and pain lowers the capacity for any activity and is not amenable to support; a permanent condition causing such fatigue or pain would indicate a person is not going to become able to work in the future. These people would need only a medical confirmation of their continued illness to show that they continue to need sickness benefit.

Of course, this assumes that the government puts in the resources to support all those sick and disabled people who could work or might be able to work if they had support. Historically, and as implied by the Green Paper proposals, this seems unlikely to happen. In this context, however, we would not need reassessments for sick and disabled people unless and until such necessary support was put in place.

People with chronic illness who currently receive ESA may legitimately be treated as having reached the 'sickness pension' stage seen in countries with a procedural approach to sickness benefits. For some, this is because they are currently unable to work and the nature of their condition is such that they are never going to see an improvement in either health or capacity for work. Examples of conditions that are known not to improve are progressive MS, Parkinson's, Motor Neurone Disease and terminal cancer. Other people on ESA with chronic illness may have conditions that in theory can improve, and do improve for some people, but which in practice are very unlikely to improve given how long the illness has endured in that patient. For some, they may always have had a version of an illness or a predisposition that meant the illness would endure for them when for other people it fades with time; for some others, it may be that had they received adequate support when they needed it, their illness would not have endured so long as to have progressed into an intractable form. The State has so long neglected to provide the healthcare and support that chronically ill people need outside of work, let alone in work, that these ESA recipients are no longer in a position where they could consider a return to work in the future.

We therefore recommend that there is no need for reassessment because:

- People with the potential to work are in touch with an Occupational Therapist who can confirm their ongoing need for support;
- People who cannot currently consider moving towards work can have their continuing illness or disability confirmed by their GP, or by a brief conversation with an OT.

Conclusion

We recommend that in the first instance, people obtain a sick note from their GP as per the current practice. This will be adequate for people with naturally self-limiting conditions where a quick return to full health is expected. GPs should also have the option of waiving any further assessment, where the severity of illness or vulnerability of the patient necessitates a complete break from work, work-related activity and any employment support measures. At this time, we cannot make predictions regarding how many people will need such a waiver or how long for. Trying to form expectations, such as expecting only 10-15% of ESA claimants to go into Support Group or one million Incapacity Benefit claimants to be capable of work, is not appropriate when data on illness severity and work capacity are not available.

For people where recovery may be slow or is uncertain, but where there may currently be some capacity for work, it is appropriate to refer these people to a service where they can have a comprehensive assessment of their support needs. The service should be provided in the first instance by Occupational Therapists, who can talk with individuals about what capacity for work they have and the full range of support they

need if they are to be able to work – not just in the workplace, but in looking for work, managing personal care and household duties, and engaging in family or social activities. A person would be assessed as fit for work if he or she, together with the Occupational Therapist, can identify three or more jobs in the open labour market which he or she can obtain and sustain without support. If an individual may be able to work with the right support, then that support will be put in place. A caseworker will be responsible for the direct provision of support according to that caseworker's profession, and ensuring that other support is made available. The caseworker may be the original Occupational Therapist or may be someone from a different profession, such as physiotherapy or counselling, according to the individual's primary need.

Disabled people will have access to sickness benefit via automatic passes on the grounds of disability. This will include people who are registered blind, have a certain percentage of hearing loss, or are recorded as learning disabled on their GP notes. Other disabilities may also benefit from having an automatic entitlement to sickness benefit. This is on the grounds that people with these disabilities all face a minimum level of difficulty with claiming benefits, complying with conditionality, looking for work and getting and sustaining work. Specialist assistance is typically needed at some or all of these points, making Jobseeker's Allowance wholly inappropriate. These people should be on a safe, adequate income with the necessary practical support that will enable them to obtain and remain in work.

Reassessments are not necessary in this system. People with some capacity for work will be in touch with caseworkers whose role is to support and advocate for them. If all the necessary support is in place, those people who can work will naturally get work. People who cannot work will be signed off either by their GP, where there is a need for protection against work-related activity; by the Occupational Therapist at the initial assessment, because it is clear that the person cannot work; or after working with the caseworker, when it has become apparent that the potential support measures are not successful. In all of this, sick and disabled people do not need to be and should not be mandated to engage. If the available support is of good quality and is holistic – looking at all the areas where a sick or disabled person needs support, not just in work – then people will take advantage of it. What sick and disabled people need is not to be forced to attend low quality employment services, but the opportunity and freedom to voluntarily access quality support.

Conclusion

This series of reports has necessarily covered a wide range of ground. We have considered how the State is systematically failing chronically ill and disabled people not just in the workplace, but at home, in the wider environment, and in their daily lives. The State does not provide the healthcare that is needed when it is needed or for as long as is needed. It does not protect people who cannot work from want. The State thus fails the two key purposes of the National Insurance/Social Security system and the National Health Service as envisaged by Sir William Beveridge. And it does so so abjectly as to be a breach of sick and disabled people's rights to decent living.

Sickness Benefit

The distinction between Jobseeker's Allowance and a sickness benefit should be simple: whether or not a person can work and is employable in the open labour market. If either of these is untrue, the person should be placed on an out-of-work benefit that differs from the current Jobseeker's Allowance in three key ways:

- it should not be either means-tested or contribution-based, in recognition of:
 - the difficulties that sick and disabled people have in building up enough National Insurance credits;
 - the long-term nature of chronic illness and disability, which significantly reduces the chances of career progression and full-time work, thus reducing lifetime income; and
 - equitable treatment means not refusing to 'pay out' (via social security) to those who have previously 'paid in' the most (via taxes and NI).
- it should be set at a level adequate for long-term living including social participation, in recognition that:
 - sick and disabled people are likely to be out of work for long periods of time even when they are capable of and seeking (some) work; and
 - meeting basic needs, having rest and leisure time, and participating in society are all human rights, regardless of our capacity for paid work.
- it should have no or minimal activity requirements, in recognition that:
 - the lives of sick and disabled people already require more effort compared to a healthy person;
 - sick and disabled people are more vulnerable to factors outside of their control; and
 - the prime reason that sick and disabled people are out of work is not lack of motivation (sick and disabled people generally have good attitudes towards work) but the limitations caused by their ill-health or disability and the lack of provision from the State for support and access requirements in their daily lives and at work.

The purpose of a sickness benefit is to provide protection against want for people who currently cannot work due to their illness or disability. This includes people who have:

- Illness or disability that is so severe that it makes work impossible, unreasonable or impracticable;
- Illness or disability that means they have a reasonable likelihood of being able to do some forms of work, but they do not have the necessary work-applicable skills unless the government funds them to gain qualifications that employers want;
- Illness or disability that permits at least part-time work, but only if:

- Necessary adjustments are put in at work;
- Necessary support is available at home;
- Necessary support is available in the wider environment; and/or
- A specialised job broker liaises with employers to create or modify jobs, and to take on new sick or disabled staff; or
- Illness or disability that needs time for medical treatment or rehabilitation before the possibility (or otherwise) of work can be addressed.

Protection from want means providing an income that is adequate to meet human rights. The minimum income needed in the UK for a single person to meet their human rights has been calculated as just under £200/week, excluding housing costs (Davis, et al., 2016). This also excludes the additional costs arising from illness or disability.

For a sickness benefit to provide a secure, stable income, it must be free from conditionality and reassessment.

We propose a new sickness benefit, which should be called 'Sickness Benefit' in order to reduce the prevalence of ambiguous names (such as Employment and Support Allowance) which allow governments to mislead the public regarding the nature and purpose of the benefit. We propose a new system of assessment, called Occupational Therapy Assessment, and a new system of support, called Occupational Therapy Support. These names will ensure that politicians, the public and recipients all have a clear and accurate conception of the nature and purpose of this new benefit, assessment and support system. This in turn should help the public to understand how, where and why their taxes are spent, and ensure that politicians cannot continue to use nebulous phrases to hide failing systems and significant cuts from the public's awareness.

Occupational Therapy Assessment for Sickness Benefit

We propose three access routes to sickness benefit:

- GP referral, when the GP has reason to believe that an isolated period of sick leave will not result in:
 - a sustained return to work;
 - a sustained ability to comply with Jobseeker's Allowance conditionality; or
 - an ability to work without additional support from either the employer or the government.
- The individual themselves, for example if they are in work and want help to remain in work before they take prolonged sick leave, or because they have reason to believe they will need more than four weeks of sickness benefit;
- Automatically after four weeks of sickness absence, bar individuals who are 'waived' by their GP either because their illness or injury will naturally resolve to full health, or because at that time it is so severe as to make an assessment of support needs inappropriate because the only suitable support at that time is a break from work or looking for work.

The referral is to a 'comprehensive hub' where sick or disabled people receive an independent Occupational Therapy Assessment. The assessment is not of the medical need for sickness benefit, because the GP's sick note has already confirmed that. Rather, it is an assessment of what support the government, and employers if an individual has a job contract, need to provide in order to enable that individual to work or become able to work. The support must cover all areas that might impinge upon an individual's capacity to work or become able to work.

The referral should include a copy of the sick note for the individual. If the individual applied, it is recommended that the individual include a 'self-assessment' of the reasons why they can't work or struggle to work. The Occupational Therapy Service would then be responsible for collecting medical evidence from the claimant's GP and any other medical professional indicated by the claimant. If the GP applied, they should include a medical report of why the GP believes an Occupational Therapy Assessment is needed, or why it should be waived and have the GP continue to provide sick notes. The Occupational Therapy Service will then, upon receipt of the GP referral, contact the individual asking if they would like to submit their own written evidence and proposing a date for a face-to-face meeting, if such a meeting is appropriate.

The Occupational Therapist should study the submitted evidence and use this to decide whether a face-to-face discussion with the individual is appropriate or necessary. The Occupational Therapist would have the option to waive a face-to-face discussion if the submitted evidence makes it clear that the person would either be harmed by a face-to-face discussion (e.g., a severe mental health crisis or severe physical illness) or would clearly not gain any benefit from such a discussion (e.g. an illness that is currently severe enough to preclude work and is also progressive). If a face-to-face discussion is considered necessary and/or of potential benefit to the claimant, then the OT should carefully consider the written evidence and what further questions to ask before calling the claimant for a face-to-face assessment. This will help to ensure that the assessment time is productive, and reduce the need for further meetings to clarify issues or to obtain further oral evidence.

The OT should consider:

- What problems the individual's health or disability causes with work;
- What problems the individual's health or disability causes outside of the workplace;
- What the individual can do without support;
- What the individual needs support in order to be able to do, and what that support is, both in and outside of the workplace; and
- What impact work would have on the individual's health, wellbeing and ability to carry out other activities;

The Occupational Therapist would draw up a proposed decision based on the conversation with the individual. This conversation may take place over one-three meetings, depending on what is appropriate for the individual. The proposed decision would be sent to the individual, complete with reasoning. The individual then has the opportunity to comment on the proposed decision and reasoning, and return it to the assessor. The assessor makes a formal decision and sends this to the individual. The individual can appeal this decision directly to the First Tier Tribunal.

The Occupational Therapist can make one of two decisions. Either:

- Fit for Work - because the assessor has identified (and included in the decision report) at least three jobs which the individual could immediately compete for and carry out in the open labour market; or
- Needs Sickness Benefit, due to:
 - Illness or disability that is so severe that it makes work impossible, unreasonable or impracticable;
 - Illness or disability that means the person has a reasonable likelihood of being able to do some forms of work, but does not have the necessary work-applicable skills and therefore needs job-specific training that is funded by the government and which is accessible to the person;
 - Illness or disability that permits at least part-time work, but only if:

- Necessary adjustments are put in at work;
 - Necessary support is available at home;
 - Necessary support is available in the wider environment; and/or
 - A specialised job broker liaises with employers to create or modify jobs, and to take on new sick or disabled staff; or
- Illness or disability that needs time for medical treatment or rehabilitation before the possibility or otherwise of work can be addressed.

Having made a decision, a person assessed as Fit for Work and who does not appeal would go on to Jobseeker's Allowance. A person assessed as needing Sickness Benefit would continue to see the Occupational Therapist who carried out their assessment, or a different caseworker depending on the individual's primary need. The OT or caseworker may refer the person to other support services, such as:

- welfare advisers (to claim other benefits);
- user-led disabled people's organisations;
- specialist charities;
- social care;
- physiotherapy;
- counselling;
- anger management;
- relationship advice;
- debt advice;
- further training or education;
- volunteering opportunities;
- other secondary NHS services;
- a Job Broker.

How often the caseworker and the Sickness Benefit recipient meet up would depend upon the individual's capacity, needs and what other support services are involved. For example, a person who would benefit from counselling or physiotherapy might not gain from seeing their caseworker again until after the course has been completed. The caseworker and Sickness Benefit recipient could then meet again to review the recipient's current needs and capabilities.

Supporting sick and disabled people

The current employment support system and that proposed by the DWP and Department for Health in their Green Paper is inadequate. Both systems rely on support workers who do not have the training, experience or understanding of how differing chronic illnesses and disabilities affect individual people and their capacity for work. Consequently, they do not know what support they need to give these people in order for them to be able to work. Neither occurs early enough, because both the DWP's and Department of Health's proposals in their Green Paper and the current Fit for Work Occupational Health scheme wait until four weeks of continuous sick leave has been taken. What is needed is a 'comprehensive hub' that includes Occupational Therapy as the primary approach for helping sick and disabled people to fulfill their own goals – whether or not they include paid work.

The current and proposed systems rely upon an assumption that the predominant reason why sick and disabled people are not in work is because they are not trying. The proposed remedy therefore is to make sick and disabled people try, through the impact of financial necessity as caused by inadequate benefits and sanctions

Conclusion

for not complying with what are often detrimental activities. But this does not cure sick people of their illness, nor cause employers to put in place the necessary adjustments, nor result in the government fulfilling its duties.

We therefore conclude that:

- In terms of employment support, the government needs to:

- Should its responsibility to:
 - provide enough jobs for the working-age population who can and want to work;
 - regulate these jobs to ensure that they are not detrimental to health; and
 - ensure that there are jobs that are designed for chronically ill or disabled people, in particular by:
 - expanding skilled trades and manufacturing; and
 - providing supported employment for those who need such an environment;
- Provide financial support to employers from all sectors and of all sizes, to cover the costs of taking on a chronically sick or disabled employee. These costs include but are not limited to:
 - subsidising employees who are less productive;
 - subsidising employees who need more time off due to their illness or disability;
 - contributing to the cost of managing workflow and staff rotas; and
 - contributing to the cost of workplace adaptations, assistive technology, BSL interpreters and other such support;
- Provide job brokers in all JobCentres who can:
 - build working relationships with local employers;
 - direct employers to the support that the government offers for employing chronically sick or disabled people;
 - work with employers to create jobs suitable for chronically sick or disabled people;
 - 'Job Match' individuals and employers; and
 - continue to support sick or disabled staff in their new role until it is clear that the role is manageable.
- Provide chronically sick and disabled people with adequate financial support for as long as they need it, by:
 - only carrying out re-assessments when they are light-touch and are for people who are not in contact with an Occupational Therapist because they have previously been assessed as unable to work and not yet ready to consider steps towards work;
 - providing benefit during volunteering and training activities; and
 - allowing immediate access to sickness benefit if someone starts work, but has to leave for health reasons. 'Health reasons' includes health that has got worse and health that has not changed but it was discovered that work was not possible or that the necessary support to sustain work was not in place.

- In terms of support outside of the workplace, the government needs to:

- Increase the remit of extra-cost benefits (Personal Independence Payment) to cover household tasks that have historically been excluded, such as laundry, cleaning, shopping, basic household maintenance, and additional utility or food bills;

- Increase funding to social care so that it is available to all who need it, and provides all the support they need. Social care should be seen as a preventative service, with the goal of reducing demand on the NHS and reducing future social care spending by ensuring that people's needs do not escalate to substantial or critical need;
- increase funding to the NHS for all services, and in particular for mental health (both crisis and long-term), GP, A&E, physiotherapy and occupational therapy;
- increase funding to local government so that day-centres and libraries can be reopened, public transport can include concessionary passes, and public environments be made more accessible;
- enforce and, if necessary, subsidise access requirements in public spaces;
- extend Access to Work to include funding for voluntary work and for training.

We strongly recommend that the government does not make work a health outcome. This is wholly inappropriate.

There are some practical elements of this system that cannot be determined by discussion with sick and disabled people. These will require testing, with appropriate data collection and analysis. These include:

- The best format for asking GPs for medical evidence;
- The time scale to give GPs for submitting medical evidence, to ensure that there is enough time for them to write and submit such evidence (bearing in mind the pressure on GP services) and bearing in mind the need for the individual to have a timely assessment. A face-to-face assessment should not occur before GP evidence has been received;
- The best format for asking individuals for self-reported evidence;
- The best way to contact individuals regarding further evidence (if it is a GP referral) or face-to-face assessments, e.g. by letter or by telephone;
- The relative merits of GP vs individual referral to the Occupational Therapy Assessment;
- Whether the decision maker should be the same person as the assessor, or a different person, and whether or not this different person should themselves be an Occupational Therapist carrying out assessments for Sickness Benefit, or should be a DWP decision maker.

The new Sickness Benefit should be predicated upon the assumption that sick and disabled people want to work, but that many simply cannot work, and others can only work if the government enables them to. It should therefore centre on the government's role in providing the jobs, access and support that sick and disabled people need if they are to be able to participate in society as full members, regardless of whether or not they are in paid work.