Written Evidence to the Health and Sport Committee: Welfare Reform Bill

November 2011

Introduction

We welcome the UK Government’s intention to simplify the benefits system, chiefly by introducing the Universal Credit. Those with long-term conditions like MS will certainly benefit from a system that is easier to understand, more user-friendly and which offers a greater degree of responsiveness and flexibility. Many people with MS want to remain in work as long as possible, so we strongly support any welfare system that incentivises and supports people to remain in work where possible.

However, it is equally important that the system is fair, continues to provide people with the financial support they need to manage the extra costs of living with a disability, and supports those who are no longer able to work due to their condition.

As a member of the Disability Benefits Consortium, a group of over 50 charities working towards a fair benefit system, we share serious concerns with a large number of other disability organisations that the Welfare Reform Bill, in its current form, could lead to those most in need losing out on the support they rely on. This would not achieve the Government’s stated aim of enabling more disabled people to start or return to work or to participate in society as fully and independently as possible.

Key concerns regarding Welfare Reform Bill

1. Employment and Support Allowance (ESA)

Employment and Support Allowance (ESA) is the new benefit for people who cannot work, or have a ‘limited capability for work’ due to illness or disability. We are concerned that the current test for this benefit and measures imposing some time-limits on claimants are both flawed and unfair.

The importance of ESA to people with MS

A recent report by the Work Foundation highlighted that:
- 75% of people with MS report that the condition has impacted their employment and career opportunities; and
- up to 80% of people with MS stop working within 15 years of the onset of the condition.

If staying in work is difficult for people with MS, even with an understanding employer in a job someone has been in for a long time, the barriers to finding new work, particularly in the current competitive job market are even greater - largely due to the unpredictability of the condition. ESA then is a vital benefit to people with MS.

Person with MS:
"I battled to stay in work with my MS for 20 years. If anything my disability will only get worse. At 58 with these problems, who’d employ me? I’ve done various interviews, but as I walk in with a stick I’m at an immediate disadvantage and it’s clear that I can’t do as many hours as they want."

The Work Capability Assessment
We believe that the current test for this benefit, the Work Capability Assessment (WCA) is flawed, and is wrongly finding too many people with fluctuating conditions ‘fit to work’.

In a recent DWP survey of ESA claimants, 53% of respondents were found to have a fluctuating condition. Yet, as recognised in the independent Harrington review of the WCA, significant problems arise for this group of people during the assessment process for the benefit. The snapshot nature of the assessment often focuses on the ‘here and now’ and fails to take the fluctuating nature of peoples’ illnesses into account, and the existing criteria do not adequately take into account factors such as pain, fatigue, stress, as well as the repeatability of functional activities, and the cumulative impact of multiple impairments.

Problems with the assessment process are resulting in high rates of costly appeals: 40% of people who appeal against an ESA decision win.

**Time-limiting contributory ESA for those in the Work Related Activity Group**

For those on contributory ESA (on the basis of their National Insurance payments) in the Work Related Activity Group (WRAG – those judged as having ‘limited capability for work’, but who are expected to be able to move back towards the workplace at some point in the future), the Welfare Reform Bill currently introduces a time limit of one year.

After 12 months of looking for work, if a claimant’s partner is earning as little as £149 per week, or working 24 hours per week, they will not be eligible for income-related ESA and may lose their benefit, leaving them with no financial support, and little incentive to access back-to-work support while faced with a degenerative condition. We are extremely concerned about this measure.

This policy is expected to impact on around 700,000 people, and the DWP has begun to contact 170,000 claimants who may lose their benefit as early as April next year, despite the fact that this policy has yet to be debated and approved by the House of Lords.

We feel that this measure should be removed, on the grounds that:

- it punishes those who remain in work for longer and build up some form of savings, or who have a working partner;
- the time-limit is arbitrary: no evidence has been cited to suggest that one year is a reasonable amount of time in which to expect an individual in the WRAG to find a job (90% of people in the Work Related Activity group on contributory ESA need support for over a year and so will face time limiting. 40% of these will lose all their ESA weekly entitlement after means-testing);
- it will add huge amounts of stress and pressure on those placed in the WRAG, many of whom face significant barriers to work, which mean that finding a job within a year is *not* a realistic prospect;
- it could therefore cause all but the very poorest, who will qualify for Income-related ESA, to be stripped of vital financial support and support back into work;
- and we believe that high levels of people with complex and fluctuating conditions like MS are being wrongly placed in the WRAG by an assessment system that the DWP has accepted is flawed. Over 40% of people with MS who receive ESA are placed into the Work-Related Activity Group.

**2. Disability Living Allowance (DLA) / Personal Independence Payment (PIP)**

Living with MS is expensive. The UK Government is clear that DLA exists to meet such extra costs experienced as a direct result a health condition, and they have stated that the new benefit, PIP will continue to do so. But the changes could mean that thousands of people with MS lose vital financial support.

**The importance of DLA for people with MS**

69 000 people with MS (almost 7 in 10 people with MS) receive some form of DLA. They rely on DLA to allow them to manage the high costs of living with the condition, spending it on a wide
range of essentials, including help around the house, informal care and prepared meals, better incontinence pads or the cost of prescriptions, or the extra costs of heating, specialist equipment and transport.

People with MS have told us:
“For a person like me, it means the difference between surviving and living. It’s the difference between having a life and not having a life.”

“The care component of DLA is spent on ready meals, pre-chopped vegetables and fruit and salad, sandwiches, hair and nail appointments, waxing (...I can no longer dry my hair, cut my nails or shave my legs, I wish I could). It is such a small amount of money in the overall scheme of things but that is something you can not put a price on.

“No care system could be flexible or responsive enough to assist someone with a fluctuating and unpredictable condition like relapsing-remitting MS. My needs change not just weekly or daily but often hourly. DLA gives me the freedom to pay for help as and when I need it and in a much more cost efficient way.”

Approach to DLA reform
Whilst there is the potential to improve DLA we do not believe this requires abolishing the benefit. We are particularly concerned at the overall objective of a ‘reduction target’ of 20% in future spending as set out in the June Budget 2010. Although the UK Government has stated its commitment to supporting disabled people, we are concerned that the approach being taken is primarily concerned with reducing costs, and that a new focus on ‘those with the greatest needs’ risks leaving high numbers of people without the support they need. This focus could have a particularly discriminatory impact on those with fluctuating needs.

Assessment criteria and frequency of assessment
The Government is proposing to introduce a new face-to-face assessment for the benefit. The draft assessment criteria published earlier this year appeared to have an extremely narrow focus, and would not fully capture the barriers that people with fluctuating conditions face in living independently. Given the experience with the WCA, we are concerned that lessons must be learnt to ensure that people with fluctuating conditions are not disadvantaged by the new assessment.

Person with MS:
“Face to face assessments are abysmal. It is just not possible for one person who does not know me, in one brief meeting, to assess my cognition, my mobility my fluctuating needs. Of course they can’t. Unless I ham it up, which is against my character, they won’t see me fall, they won’t see me shut a door on myself because my co-ordination doesn’t work, where are they when pain stops me sleeping or I can’t get off the floor myself.”

In addition, we believe that for people with long-term, degenerative conditions like MS, there is no need for repeated face-to-face reassessments.

Evidence from the MS Society indicates that face-to-face assessments for benefits can be extremely stressful. In a 2010 survey by the Disability Benefits Consortium (DBC), more than half of those who had been through an assessment for ESA found it stressful and more than four in ten said it made their condition worse because of the stress and anxiety caused. Stress has been shown to exacerbate MS, and in some cases even to bring on serious relapses. Putting DLA claimants with MS (and particularly the progressive form of the condition) through repeated and stressful reviews is therefore not only unnecessary expense for a system which is supposed to be designed to save the DWP money, it risks unintended and serious negative consequences for the health and wellbeing of the individuals at stake.
We strongly urge the UK Government then to ensure that people with MS receive longer awards with fewer and less onerous reassessments, and call for a provision in the Bill to ensure that people will be placed onto the benefit on the basis of paper evidence wherever possible.

**Extending the qualifying period from 3 to 6 months**
The Bill extends the qualifying period before claimants can receive PIP from 3 months under DLA to 6 months under PIP. People must also be expected to continue to demonstrate a need for a further 6 months. We are concerned that this will unfairly disadvantage people with sudden onset needs, who will have to wait an additional 3 months to get the vital funds to help them to manage their condition – for example, those with MS who experience a bad and disabling relapse. By the time they are able to apply for PIP, the period of greatest need may well have passed, and they may have experienced significant costs and generated significant debts and difficulties. We recommend that this should be amended to state that the individual must simply have experienced or be expected to experience the needs for at least a total of one year – whether that is forward or backwards-looking should be immaterial.

**Removing the mobility component of DLA/PIP from those in residential care**
We believe that taking the mobility component away from those in residential care would be a disappointing and regressive step that would deny many people in residential care the support to get out and about and retain a small slice of independence. The government has proposed this cut on the basis that the needs of people in residential care homes are met by their local authorities. But evidence from provider organisations, local authorities and individuals shows that this is not true. We believe that this power should be entirely removed from the Bill.

The Government is currently reviewing this policy, but through an internal and opaque process. We therefore support the independent Low Review, which was set up by Mencap and Leonard Cheshire Disability to ensure that a transparent and open review takes place on this issue, and look forward to the results of the review.

**About MS**
Multiple sclerosis (MS) is a neurological condition which affects around 100,000 people in the UK. 10,500 people are living with MS in Scotland – one of the highest rates anywhere in the world.

Most people are diagnosed between the ages of 20-40, but it can affect younger and older people too. Almost twice as many women have MS than men.

**Further information**
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