

The Haemophilia Society Submission to the Health, Disability and Work Green Paper

About us

The Haemophilia Society are the only UK wide charity for everyone affected by a bleeding disorder: a community of members, supporters and healthcare professionals.

Our work is driven by a small staff team, based in London and working alongside volunteers from all over the UK. We are governed by a board of trustees.

We are:

- the UK's only independent charity for everyone affected by a bleeding disorder
- a community of individuals and families, healthcare professionals and supporters.

Our work enables people to:

- lead fulfilling lives
- make informed choices about their treatment and care
- support and inspire others to do the same.

As a health charity, we work alongside the NHS to:

- provide easy access to information and opportunities
- influence national policy and practice to make the care and treatment of bleeding disorders consistent, effective and accessible to all
- enable the voices of all people with bleeding disorders to be heard.

As well as living with an inherited bleeding disorder and associated joint damage and arthritis, many members of our community were infected with blood borne viruses in the 70s and 80s including Hepatitis C and HIV from their NHS treatment with contaminated blood products.

Introduction

Overall, we are pleased that the Government has conducted this consultation and welcome the commitment to substantially reduce the disability employment gap.

We support the principle laid out in the ministerial foreword that the system should provide “work for all those who can, help for those who could and care for those who can’t”.

However, this needs to be balanced against a system which is administered fairly and compassionately. It also needs to be appropriately funded so people get the support they need.

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Our key recommendations are:

- The ESA application process needs to provide more guidance for applicants
- Vulnerable claimants should be better supported in their applications and assessments
- The Government should bring forward proposals to reform the WCA
- Certain individuals affected by the Contaminated Blood Scandal should be passported to receive PIP and ESA without the need for assessments
- There should be no new conditions placed on people in the support group
- The Government should accept that work is not always a positive health outcome
- The planned cut to the ESA-WRAG rate should not take place
- Back to Work support should be appropriately funded to provide enough suitably qualified work coaches
- There should be transparency in how back to work funding is spent
- Higher expectations should be set for employers to support people to stay in or return to work
- More data should be shared between assessments and public bodies subject to safeguards

We have included more detail on each of these points below.

The WCA and the Appeals process

Needs of disabled people

The Work Capability Assessment (WCA) needs to be conducted with the needs of disabled people in mind. Applicants must be treated with sensitivity and understanding of their conditions.

Applicants with multiple conditions and in particular those who have mental health as well as physical problems, need to be guided through the process of application. We would support a vulnerable claimant process that provides more guidance for people that need it. However, we believe all applicants would benefit from better guidance through the application and assessment process.

The WCA

Applicants are not being appropriately assessed as to their fitness to work. This is reflected in recent government statistics showing that 62% of appeals are successful. The Government needs to bring forward proposals to improve the initial assessments for disabled people.

In particular, we would like to highlight the issues for people with a fluctuating condition. The 2013 DWP review of the WCA also expressed concerns and led to the development of alternative assessments however these have still not been implemented.

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Finally, we believe the WCA is overly focussed on functional ability rather than considering barriers that individuals face with getting into work more holistically. We suggest that a reformed WCA would take into account barriers to work including housing issues, relationship breakdown, availability and success of treatment, difficulties travelling to work and stigmas.

There should also be greater consideration of the availability of suitable work. For example, our members may not be able to do work that is manual, involves repetitive actions or requires extended walking.

We would also suggest that evidence from Healthcare Professionals (HCPs) need to be requested more regularly and considered more fully.

We would also like to see evidence from other HCPs for example physiotherapists and occupational therapists being more frequently requested and considered.

Appeals and Tribunals

The appeals process is overly stressful and despite the high success rate of appeals many people are put off appealing against incorrect judgements.

The 2015-16 Disability Benefits Consortium Big Benefits Survey highlighted the stressful nature of the ESA assessment. 92% of respondents who had had a WCA (n=274) agreed or strongly agreed that the assessment was stressful, while 88% agreed or strongly agreed that the assessment made their health worse because of stress/anxiety.

We have also received reports that in some cases, the very fact that someone affected appealed against a wrong decision has been used against them as evidence that they were fit to work. It is inappropriate that challenging the correctness of a judgement is taken as evidence of fitness to work.

Passporting to Benefits

We were also involved in preparing the submission from the APPG on Haemophilia and Contaminated Blood (to which we provide the Secretariat) regarding passporting to PIP and ESA for certain people affected by the Contaminated Blood Scandal. We have included that submission as a separate document.

This proposal explains how and why this community should not be subject to assessments and reassessments for PIP and ESA.

Eligibility

Support group conditionality

We disagree with the proposals to introduce health and employment support for people in the support group on a mandatory basis. The support group is for those people who are not

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able to undertake work related activity and where any work could be detrimental to their health.

We do not agree with the suggestion that this group is 'written off' by the current system. Instead accurate judgements need to be made on whether someone is fit to work, able to undertake back to work activity or not currently able to work. Those in the final category should be entitled to ESA without any associated conditions.

Work is not always a positive health outcome

There will be people for whom work will not lead to better health outcomes. The Government should be clear that there are people who are unable to work or for whom work will lead to a deterioration of their condition.

The joint damage and arthritis caused by bleeds is irreversible and future bleeds will exacerbate the damage that already exists. For this reason the impact of a bleeding disorder is progressive and will only get worse over time. If someone is unable or finds it difficult to work because of the impact of their bleeding disorder this will only get worse over time.

Support received

The amount of financial support for individuals

The Haemophilia Society oppose the forthcoming 30% reduction to the Work Related Activity Group (ESA-WRAG) rate and the equivalent 'Limited Capability for Work' group within Universal Credit from 1st April 2017.

The Government have stated that the reason behind cutting ESA-WRAG by £1500/year is to *'remove the financial incentives that could otherwise discourage claimants from taking steps back to work.'*

However, there is considerable evidence that these cuts will have a significant, harmful impact on disabled people and push them further from the workplace. Research conducted by the Disability Benefits Consortium showed that of around 500 disabled people in receipt of ESA-WRAG:

- Almost 70% of disabled people said cuts to ESA will cause their health to suffer
- A third said they could not afford to eat on the current WRAG rate
- Almost half said it would probably delay their return to work.

We also note the findings of the Work and Pensions Select Committee, which raised concerns that *'the Department's rationale for its decision [to cut the WRAG rate] rests on limited evidence.'*¹

¹ <https://www.publications.parliament.uk/pa/cm201617/cmselect/cmworpen/56/56.pdf>

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Supporting people into work

Skills of the work coaches and support provided

The Haemophilia Society support the principle of providing a more personalised approach to employment support for disabled people. However, we are concerned that the proposed package of support may not provide the personalisation required.

Good work coaching will provide examples of jobs and roles that match the skills and abilities of the individual but needs to take into account restrictions on what will be safe for the individual. For someone with a bleeding disorder roles that require repetitive movements, extended walking or certain manual tasks will not be appropriate.

We disagree with the timing of the health and work conversation immediately following ESA application. It will not be clear prior to the WCA what support people will need and indeed they may be placed in the support group if they are judged to not be able to engage in back to work activity.

While we would support any extra back to work support, having a mandatory meeting that may put pressure on individuals to overstate their ability to work prior to their Work Capability Assessment is not appropriate.

Availability of funding to meet the Green Paper's ambitions

Although the Green Paper sets out comprehensive proposals for fundamental reform of the way disabled people are supported to remain in work and helped back into work, we are concerned that the availability of funding will be insufficient to meet these ambitions.

We note, for example, that the funding for the Work and Health Programme stands at only £130m². This is a fraction of the £2.2 billion that had been paid to Work Programme providers until December 2015³.

It is also unclear as to whether the estimated £640m saving from the cut to the ESA-WRAG as a result of the Welfare Reform and Work Act⁴ will be entirely recycled into the provisions outlined in the Green Paper.

We would request greater clarity on what funding will be available for work coaches and other green paper proposals and reassurance that it will be sufficient.

Commitments from employers

The ability for people with long-term health conditions to stay in or return to work is also highly dependent on employers making required adaptations and changes to the work environment and culture.

² <http://researchbriefings.parliament.uk/ResearchBriefing/Summary/CBP-7845#fullreport>

³ <http://researchbriefings.parliament.uk/ResearchBriefing/Summary/SN06340#fullreport>

⁴ <http://www.parliament.uk/documents/impact-assessments/IA15-006B.pdf>

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The Government should seek greater commitments from employers to implement policies that help people with long term health conditions stay in work.

Our members specifically noted that they would welcome more flexibility in working hours and working from home. This would, for example, help to avoid crowded public transport and make it easier to attend hospital appointments. Individuals may also need additional time to manage their treatment and bleeding episodes and require more frequent breaks due to pain or fatigue which are common among people with bleeding disorders.

Members have also suggested that they would appreciate better dialogue for agreeing a staged return to work where they could increase their hours from part-time to full-time to avoid being forced in too quickly. We would support any proposals to reform Statutory Sick pay that would help facilitate this.

Other

Data sharing

With appropriate safeguards in place we would support proposals to better share information between ESA and PIP assessments, local authorities and from the NHS in order to ensure individuals are getting all the support they require and are entitled to.

We also would like to see greater consideration of housing needs and availability of public transport in assessments and support provided. There may individuals who in the same health circumstances need different support to overcome barriers such as unsuitable housing and required adaptations or heavier reliance on owning and maintaining a car.

Greater data sharing from local authorities and the Department for Transport may be able to facilitate this.

Recording employment status in clinical settings

We support the suggestion to ease and standardise recording employment status in clinical settings. This can help to ensure treatments ease the return to work and can also aid Healthcare professionals in providing more relevant information where someone is not able to work.

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