Five things you and your party can do for disabled people

deafblind uk

Muscular Dystrophy Campaign

nras
National Rheumatoid Arthritis Society

mencap
The voice of learning disability

sense Scotland

nawra
national association of welfare rights advisers

MS
Multiple Sclerosis Society

action for m.e

PARKINSON'S UK
CHANGE ATTITUDES.
FIND A CURE.
JOIN US.

British Lung Foundation

The National Autistic Society

DBC

Terrence Higgins Trust

sense
for deafblind people

Disability Rights UK

ais
autism in scotland

Leonard Cheshire Disability

Stroke association

mnda
motor neurone disease association

contact a family
for families with disabled children

RNIB Supporting people with sight loss

Papworth Trust

TPT
Thomas Pocklington Trust

epilepsy society

CLIC Sargent
for children with cancer

CHILD POVERTY ACTION GROUP

TRANSFORMING THE UK'S RESPONSE TO HIV
NAT

St Joseph's Hospice

DBC Disability Benefits Consortium

About the DBC

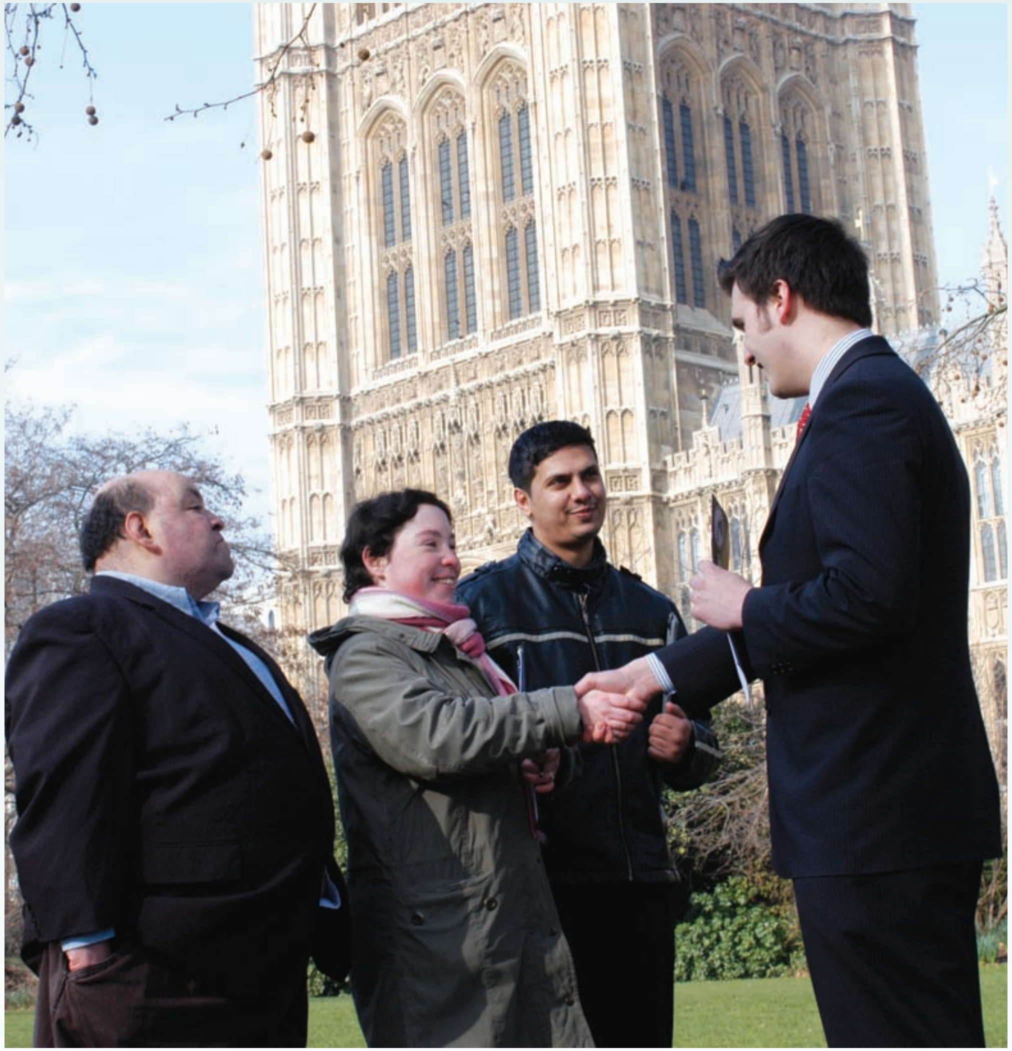
The Disability Benefits Consortium (DBC) is a national coalition of charities and other organisations committed to working towards a fair benefits system.

Using our combined knowledge, experience and direct contact with millions of disabled individuals and carers, we seek to ensure Government policy reflects and meets the needs of all disabled people.

Our objectives

The DBC is committed to achieving a social security system that:

- Meets the needs and facilitates opportunity for disabled people;
- Is informed by the needs and experiences of disabled people;
- Is fair in its design and administration;
- Is transparent and accountable;
- Supports disabled people to meet the extra costs associated with disability;
- Reflects the reality of the challenges faced by disabled people seeking work;
- Recognises the individual needs of all disabled people (regardless of factors such as impairment and age);
- Contributes towards tackling disability poverty and interacts with other government measures to achieve this;
- Tackles misunderstanding about disability and the support disabled people may need from the benefit system.



Introduction

1 in 6 of us has a disability[1], and any one of us could need social security at any time in our lives.

We all want to believe that social security measures are in place so that we will get the support we need if sickness or disability means we can't work, or that we need money to cope with the extra costs we might face. In the UK we are very lucky to have a system that is intended to offer this kind of support.

However, our combined knowledge, experience and direct contact with millions of disabled individuals and carers, has shown us that the system is not currently up to task. It is failing to adequately meet the needs of many disabled people who rely on it.

This needs to change.

We all have a role in ensuring that we can get the support we need when we need it – we call on all Parliamentarians and political parties to commit to our recommendations and help ensure that in times of sickness or disability, no-one is left without the support they need.

For a glossary of terms please see p.9

We call on political parties to commit to our 5 key asks:

1. **The next government should recognise the extra costs disabled people are forced to pay, and take steps to tackle this financial disadvantage in the longer term.**
2. **The next government should ensure appropriate support for disabled people to work, and security for those who cannot.**
3. **The next government should take a lead role in changing the way society talks about welfare.**
4. **The next government should ensure overall spending on financial support for disabled people is allocated on the basis of need, not pre-determined limits to avoid disabled people losing the support they need in years to come.**
5. **The next government should take action to ensure that a person's disability does not mean that they are disproportionately affected by policy decisions.**

The next government should recognise the extra costs disabled people are forced to pay, and take steps to tackle this financial disadvantage in the longer term.

- Disabled people spend £550 a month on costs directly associated with their disability on average. One in 10 disabled people spend over £1,000.[2]
- 80% of disability-related poverty is caused by extra costs.[3]

What disabled people tell us

Malcolm has Fibromyalgia, Asthma and Atrial Fibrillation. He told us:

“Without Disability Living Allowance (DLA) I would only be able to get to a few local shops and would be devoid of any social life. I would not be able to afford to run a car, let alone lease a Wheelchair Accessible Vehicle. I would become even more depressed than I am already. I have used my DLA to provide a reclining chair to stand me up and an adjustable bed to alleviate pain. Keeping me independent means that I need less care and this is more cost effective in the long term.”

Harriet has multiple sclerosis (MS). She told us:

“I'm really worried about the rules for Personal Independence Payment (PIP) that mean if I can walk further than 20 metres I could be at risk of losing out on the highest rate of the mobility component of the benefit. This is the part of the payment I currently use for my Motability vehicle.

The days when I can walk slightly further than this distance are no cheaper than the days when I can walk 20 metres or less. I am still unable to access most shops and local services in our area without my wheelchair. I am still unable to get to the top of our road to access public transport. I am still unable to do the family shop.”

What you and your party can do

- Ensure that changes to the criteria for benefits designed to help with the additional cost of disability take into account the real and immediate costs disabled people face. For example, take a stand against the new 20 metre rule for PIP, which means that many of those who can walk just a step more than this distance will no longer qualify for the highest rate of mobility support.
- Ensure that disabled people do not face financial hardship due to delays in the assessment process by opposing plans to extend PIP before it is fit for purpose. Make sure your party aims to put plans in place to provide support for those in severe financial hardship as a result of the delays.
- Compel benefit assessors to consider evidence from professionals throughout assessment processes to ensure the results are as accurate as they can be, and that face to face assessments are only conducted when absolutely necessary.
- Push for benefit application processes to be made completely accessible to all disabled people.
- Ensure that extra cost payments, like PIP, are not taken as part of someone's income when their eligibility for other types of support, such as Discretionary Housing Payments (DHP) or social care, is being considered.
- Recognise that extra cost payments for older disabled people, such as Attendance Allowance (AA), are vital to enabling independence.
- Work to reduce the extra costs of disability – for example, ensure that the next government uses its purchasing power to drive down prices of disability related equipment and services.

The next government should ensure appropriate support for disabled people to work, and security for those who cannot.

- Back-to-work support is not working well enough: only 5% of people in the Work Related Activity Group (WRAG) of Employment and Support Allowance (ESA) have moved into work through the Work Programme, compared to the original target of 16.5%.[4]
- Over 80% of welfare rights advisors surveyed feel that the current test for out of works benefits, the Work Capability Assessment (WCA), fails to accurately identify the correct outcome for disabled claimants.[5]
- At the time of writing claimants appealing their decision on ESA are currently successful in nearly half of cases.[6]

What disabled people tell us

Graham has Parkinson's Disease. He said:

> *“After reluctantly giving up work after reducing my hours, I applied for Incapacity Benefit. This year I was sent a form to fill in for ESA. It was not easy to do. I received a letter from the Department of Work and Pensions (DWP) to tell me I was assessed as being able to return to work eventually and put into the WRAG.*
>
> *I naively assumed that having a progressive neurological condition, that had forced me to give up work, and my condition having got worse since being on Incapacity Benefit, alarm bells would ring. The unpredictable and debilitating symptoms now make the prospect of working impossible. If I could work I would gladly do so.*
>
> *I was invited to attend the Job Centre to talk about my return to work plan, which in the end took place over the phone with the advisor saying he could not think of any support that would be relevant to my situation.*
>
> *I appealed this decision and I was put into the Support Group.”*

What you and your party can do

- Reform the Work Capability Assessment to ensure it is accurate and that assessment criteria reflect a person's impairment, its fluctuations, and the impact it can have on their ability to work.
- Compel assessors to consider evidence from professionals throughout the assessment process for out of work benefits to ensure that the results are as accurate as they can be, and that face to face assessments are only conducted when absolutely necessary.
- Ensure that back-to-work support for people found fit for work or placed in the WRAG of ESA is linked to the barriers identified in their assessment.
- Review the conditions and sanctions being placed on disabled people for them to continue receiving the financial support they need.
- Ensure that benefit rules do not unfairly impact on disabled people who are overcoming barriers to, or are unable to work. For example, by reviewing the 12-month time limit on Contributory ESA for those in the WRAG.
- Amend rules for Universal Credit (UC) so that support currently available under the Disability Element of Working Tax Credits is retained.

The next government should take a lead role in changing the way society talks about welfare and disability.

- In the DBC's Big Benefits Survey of over 3000 disabled people, 13% of respondents said they had been a victim of hate crime because they need to claim benefits, while 72% felt that society looked down on them for the same reason.[8]

What disabled people tell us

Neil has a learning disability. He told us:

> *“I have a learning disability. I want to work, but it's hard and I don't get any help or support.*
>
> *People call me “benefits boy” and a “scrounger”. Once I was asked if I worked and I said “no, I'm on benefits”, and then they told me I was a retard and a scab.*
>
> *I don't like people saying these things to me. I don't think that it's fair. It isn't my fault that I can't find a job. It makes me feel worthless.”*

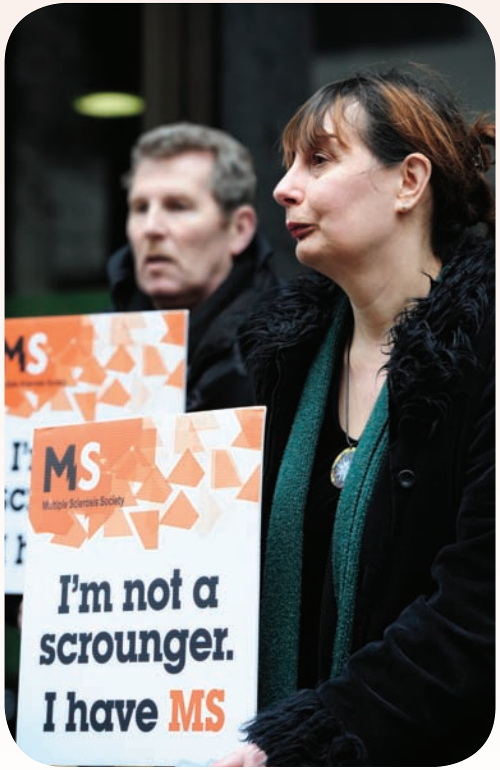
Sophie has a mental health condition, she said:

> *“I live with the dread of being asked “where do you work?” because of public opinion. With every medical or time I need to go to a benefits office I am made to feel like I don't deserve anything and that I'm begging. I would rather be cold and hungry than have to go there and feel like that again.”*

What you and your party can do

- Use responsible language that does not victimise people who need support to lead their daily lives.
- Acknowledge the role that your party has in influencing the content of media stories, and only release accurate and contextualised statistics.
- Take active steps to reduce the harassment and abuse of disabled people in your constituency, and meaningfully engage with disabled people in your area.
- Promote the positive impact that sustainable and comprehensive support for disabled people can have, and oppose policies that serve to reinforce negative perceptions about those who need support.

Neil



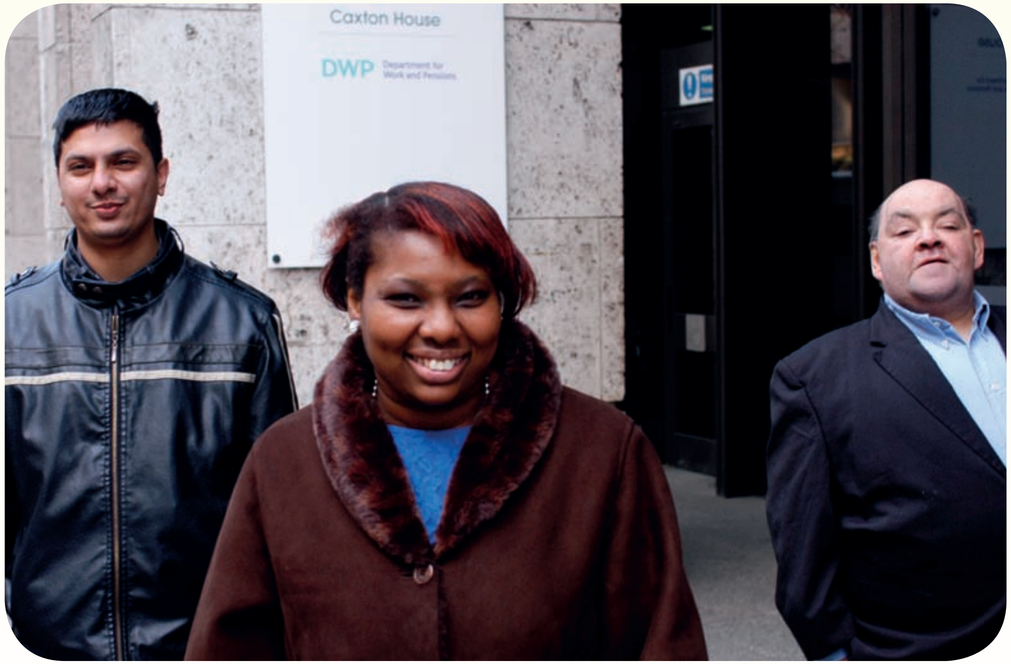
The next government should ensure overall spending on financial support for disabled people is allocated on the basis of need, not pre-determined limits to avoid disabled people losing the support they need in years to come.

Support for disabled people needs to be future proofed. In March 2014 Parliament agreed that in 2015/16 the Treasury will spend a maximum of £119.5billion on certain social security benefits, including key disability benefits such as ESA, DLA and PIP.

The number of people who are disabled is set to rise[9] and we are concerned that a cap on spending will mean that there is not enough money to adequately protect those that need vital financial support. We are fearful of the longer term impact this could have on disabled people.

What you and your party can do

- Put measures in place to prevent disabled people losing out due to unforeseen problems with reforms. For example, delays in rolling out PIP and Universal Credit will reduce the expected savings of these reforms. These reductions should not lead to a breach of the overall cap on Annually Managed Expenditure (AME).
- Ensure your party's policy on social security spending has the flexibility to respond to the needs of disabled people, the economy and other external factors. No benefit should be subject to cuts because of a rise in spending in other areas. The cap on AME must apply to spending over more than a year, and must be nuanced enough to protect disability benefits.
- Support preventative policies to tackle some of the underlying causes for social security spending – unemployment, low pay, housing, social care and childcare costs.



The next government should take action to ensure that a person's disability does not mean that they are disproportionately affected by policy decisions.

Over the last decade, disabled people have been hit by a multitude of changes, introduced by successive governments. These changes are significant for disabled individuals who could be living on as little as £72.40 a week.

The Institute for Fiscal Studies (IFS) recently published research that looked at the impact of 35 benefit and tax changes on disabled people in Wales.

The report calculates that working-age households in Wales with someone eligible to claim disability benefits will see a loss of nearly £34 a week (or 6.5% of net income). This compares to an average of nearly £10 a week (1.5% of net income) among other working-age households.[10]

What you and your party can do

- Ensure that your party fully considers how individual policy changes combine to impact on disabled people. Only then will it be possible to understand the full impact of policy decisions made.
- Detect and resolve problems in policy by piloting and comprehensively evaluating new changes before they are rolled out more widely.
- Protect crucial forms of support during attempts to streamline the welfare system. For example, the support provided by the Severe Disability Premium must not be lost when six means-tested benefits are brought together under Universal Credit.
- Strengthen the new Inter-Departmental Ministerial Group on Disability (in a similar way to the Child Poverty Unit) by ensuring it reports to Parliament each year on how successfully they have improved the lives of disabled people using a set of criteria co-produced with disabled people.

Glossary of Terms

Disability Living Allowance (DLA): DLA is an in and out of work, tax-free benefit for disabled children and adults to help with the extra costs of living with a disability. DLA is being replaced by Personal Independence Payment (PIP). DLA has two components, one to help with care costs, and one to help with mobility costs. Each of these components is paid at different rates to people with different levels of need.

Personal Independence Payment (PIP): PIP began to replace DLA in April 2013 and it is available to those between 16 and 64. The majority of those applying for PIP will have a face to face assessment and all PIP awards will be periodically reviewed. Like DLA, PIP has two components, one to help with care costs and one to help with mobility costs. Each component is paid at two different rates, standard or enhanced, depending on an individual's level of need.

Employment and Support Allowance (ESA): ESA provides financial support for people who are unable to work or have limited capability to work due to illness or disability. The Work Capability Assessment (WCA) is used to assess eligibility for the benefit (see below). The rate a claimant receives depends on the group they are placed in, and whether they qualify to receive the contribution based amount (based on the number of national insurance contributions they have made) or the income related amount (based on their level of income). The three groups are:

- **Fit for Work:** Those declared fit for work are not eligible for ESA. People declared fit for work often move on to claim Job Seekers Allowance (JSA).
- **The Work Related Activity Group (WRAG):** Those in the WRAG are expected to undertake work related activity and can be subject to conditions and sanctions if they fail to do so. Some people in this group will have their payments limited to 12 months depending on their income. Those in the WRAG receive a smaller payment than those in the Support Group.
- **The Support Group:** Those in the support group receive the highest level of payment and are not expected to undertake work related activity. Payments are not time limited but individuals are reassessed periodically.

Work Capability Assessment (WCA): The WCA is used to assess eligibility for ESA. It is a points-based assessment that measures a claimant's functionality. For most people the WCA involves a face to face assessment with an assessor from an independent company on behalf of the government.

Universal Credit (UC): Universal Credit is a single benefit that is paid to claimants if their income falls below a certain level. Universal Credit is being introduced in stages and will eventually replace most existing benefits and tax credit.

Job Seekers Allowance (JSA): JSA is the benefit paid to help people look for work. Claimants must actively demonstrate they have been searching for a job to keep getting payments.

Attendance Allowance (AA): is a benefit for people aged 65 or over who need help with personal care as a result of a physical or mental disability.

References

[1] DWP. Family and resources survey 2011/12,
https://www.gov.uk/government/publications/family-resources-survey-201112, accessed 15 Sept. 2014.

[2] E. Brawn, Priced Out: Ending the financial penalty of disability by 2020,
www.scope.org.uk/Scope/media/Images/Publication%20Directory/Priced-out.pdf?ext=.pdf, 2014,
accessed on 26 Sept. 2014.

[3] A. Sen, The Idea of justice (Belknap Press, 2009).

[4] C.Hale, Fulfilling Potential? ESA and the fate of the Work-Related Activity Group,
http://www.mind.org.uk/media/933438/2014-support-not-sanctions-report.pdf, accessed 5 Sept. 2014

[5] The DBC surveyed welfare rights advisors in July and August of 2014 to identify any improvements in their clients' experiences of the WCA since 2010. The survey received over 200 responses.

[6] Ministry of Justice, Tribunals Statistics Quarterly, January to March 2014,
www.gov.uk/government/collections/tribunals-statistics, 2014, accessed 15 Sept. 2014.

[7] Home Office, Office of National Statistics and Ministry of Justice, An overview of hate crime in England and Wales.
www.gov.uk/government/uploads/system/uploads/attachment_data/file/266358/hate-crime-2013.pdf 2013,
accessed 3 Sept. 2014.

[8] The DBC conducted its Big Benefits Survey between July and August 2014. It posed a series of quantitative and qualitative questions on disability benefits to disabled people to which over 3300 responded.

[9] Figures from the Family Resources Survey show that the number of disabled people has grown by over 1 million since 2002. DWP. Family and resources survey 2011/12,
https://www.gov.uk/government/publications/family-resources-survey-201112, accessed 15 Sept. 2014.

[10] D. Phillips, Institute for Fiscal Studies, The distributional effects of the UK government's tax and welfare reforms in Wales: an update, http://www.ifs.org.uk/publications/7258, 2014, (accessed 29 September 2014).

Notes

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