

Benefiting disabled people?

A report by the Disability Benefits Consortium looking at the support offered to disabled people and people with a health condition by the benefits system and how this support could be improved.

EXECUTIVE SUMMMARY

Disability benefits are undergoing massive change, with Incapacity Benefit being replaced by Employment and Support Allowance (ESA) and Disability Living Allowance (DLA) due to be replaced by Personal Independence Payment (PIP). This report is based on the findings of surveys by the Disability Benefits Consortium and Disability Alliance, and examines people's experiences of the benefits system. We found that:

- Over half of those respondents who had been for a medical assessment for ESA found it stressful and more than four in ten said it actually made their health condition or impairment worse because of the stress and anxiety caused.
- Over half of those respondents who had received a decision on their application for ESA didn't agree with the decision and of these, half planned to appeal.
- Of the 61% of respondents not in work nearly one third said that their impairment or health condition means that they cannot work at all.
- Just 4% of those respondents not in work said that they do not want to work.
- Less than 10% of current DLA recipients state that the benefit covers all their disability-related additional costs of living, with DLA most commonly used towards items like transport (89%), heating/laundry (68%) and aids/equipment (58%).

Our findings show that:

- The assessment process for ESA must be radically reformed to more accurately measure the impact an individual's impairment has on their ability to work and must be carried out by healthcare professionals who have a better understanding of disability, and in particular how impairments or conditions can fluctuate, or can be affected by fatigue or pain.
- It is wrong to limit the amount of time some people can claim ESA when in some cases people are unable to return to work.
- Changing the benefits system with Universal Credit will not address the key barriers preventing disabled people working or working more hours.
- Reducing the amount spent on DLA for working age people risks pushing more disabled people into poverty.

THANK YOU

Whilst all DBC organisations have supported the surveys and report, special thanks must go to the following:

- Rethink
- Leonard Cheshire Disability
- Disability Alliance

INTRODUCTION

The Disability Benefits Consortium (DBC) is a national coalition of over 40 different charities and other organisations committed to working towards a fair benefits system.¹ Using our combined knowledge, experience and direct contact with disabled individuals and carers, we seek to ensure government policy reflects and meets the needs of all disabled people.

The benefits system provides incredibly important support for many disabled people, through out of work benefits like Employment and Support Allowance or through benefits that help meet the extra costs associated with disability like Disability Living Allowance.

Despite improvements brought about through legislation like the Disability Discrimination Act and now the Equality Act, disabled people continue to face major barriers throughout society, and particularly in accessing employment. This means that disabled people are far more

¹ DBC members: Action for Blind People, Action for M.E., Age UK, Arthritis Care, Breast Cancer Care, Carers UK, Child Poverty Action Group, Citizens Advice, Clic Sargent, Cystic Fibrosis Trust, Deafblind UK, Disability Alliance, Every Disabled Child Matters, Guide Dogs, Haemophilia Society, LASA, Leaning Disability Coalition, Leonard Cheshire Disability, Macmillan Cancer Support, Mencap, Meningitis Research Foundation, Mind, Motor Neurone Disease (MND) Association, MS Society, Muscular Dystrophy Campaign, National AIDS Trust, National Autistic Society (NAS), National Deaf Children's Society, Parkinson's UK, Rethink, Royal Association for Disability Rights (RADAR), Royal National Institute for Deaf People (RNID), Royal National Institute of Blind People (RNIB), RSI Action, Scope, Sense, Skill, Sue Ryder, TUC, United Response, Vitalise.

likely to live in low-income households, and far more likely to rely on benefits for a large part of their income².

There is very clear evidence of the disadvantage that disabled people can face in achieving a decent standard of living:

- Over 40% of disabled respondents to a major survey have said that they struggle to manage on their current income;³
- Disabled people are twice as likely to have no qualifications as non-disabled people;⁴
- Nine out of ten employers believe that there is still discrimination against disabled people in employment and recruitment.⁵

These, combined with other factors, mean that disabled people are twice as likely to live in poverty as non disabled people. Action is needed to try to reduce the poverty gap between disabled and non-disabled people, and the benefits system plays a crucial role in this.

Changes to benefits will inevitably have a disproportionate impact on disabled people, either positive or negative. A benefits system that actively supports more disabled people to find work will have a positive impact, whilst a system that reduces the support that people have to

² Parckar, G. (2008) Disability poverty in the UK, Leonard Cheshire Disability

³ Gore, E et al (2009) Disability Review 2009, Leonard Cheshire Disability

⁴ Data from Labour Force Survey

⁵ Survey of employers conducted by Personnel Today:

<http://www.personneltoday.com/articles/2007/12/03/43501/discrimination-against-disabled-still-rife-says-report.html>

meet their additional costs will inevitably make already unacceptable levels of disability poverty even worse.

Any reforms to the welfare system must consider the impact on disabled people, and the impact on levels of disability poverty. The benefits system does need to work better for disabled people, but we are concerned that many of the reforms currently being proposed will actually lead to an even higher number of disabled people living below the poverty line in the UK and this cannot be right.

Our research

From August to October 2010 the DBC carried out a survey asking disabled people about their experiences of the benefits system and over six thousand people responded. In addition Disability Alliance conducted a survey of people's experience of Disability Living Allowance from December 2010 to February 2011 with over 1700 people responding. This report shares their experiences of work and the support offered by the benefits system.⁶

⁶ The following impairments are all reflected in the DBC survey results: Acquired Brain Injury, Arthritis, Bleeding disorder, Autism Spectrum Disorder, Blind/partially sighted, Breast cancer, Cancer, Carpal Tunnel Syndrome, Cerebral Palsy, Deaf/hard of hearing, Deafblindness, Hepatitis 'C, HIV, Learning disability, ME, Mental Health Condition, MS, Motor Neurone Disease, Muscular Dystrophy, Musculoskeletal, Parkinson's, Physical impairment not requiring the use of a wheelchair, Physical impairment requiring the use of a wheelchair, Repetitive Strain Injury, Speech impairment, Stroke.

SUPPORT FOR PEOPLE NOT IN WORK

Of those people who responded to the DBC survey just 1 in 5 (19%) were in full time paid employment and of the 61% not in work nearly one third said that their impairment or health condition means that they cannot work at all.

In addition, many disabled people face restrictions to the kind of work they can do. Of those respondents not in work, 27% said that their impairment or health condition means that there are some jobs they cannot do, with 39% of those in work saying the same. Importantly, just 4% of those respondents not in work said that they do not want to work. This is in contrast to widespread media portrayal of benefit claimants as reluctant to work.⁷

There are now two main benefits for people not in work:

Jobseeker's Allowance (JSA) is the main out of work benefit for working age people and in return for their benefit claimants have to show that they are trying to get a job.

⁷ Nearly 2 million on sickness benefits for years could be fit to work, Daily Mail, 15th March 2011; 75% on sick are skiving, Daily Express, 26th January 2011; 400,000 'were trying it on' to get sickness benefits: 94% of incapacity claimants can work, Daily Mail, 26th January 2011; Two-thirds on disability benefits are fit to work - costing taxpayers £500million, Daily Mail, 1st February 2010; Just one in 20 benefit applicants 'permanently unable to work', Daily Telegraph, 14th October 2009; 9 out of 10 on the sick well enough to work, The Sun, 14th July 2009

Employment and Support Allowance (ESA) is the benefit for people unable to work due to ill health or disability. It was introduced in 2008 and people who get Incapacity Benefit are now being tested for ESA.

People awarded ESA are either placed in the Work Related Activity Group (for those expected to find work) where they receive a lower rate of benefit and have to do things aimed at preparing them for work or the Support Group (for those not expected to work) where they receive a higher rate of ESA and do not have to do anything in return for their benefit.

ESA is the benefit designed to support disabled people and people with a health condition. Just under one thousand respondents to the DBC survey had applied for ESA. Below we look at how it is working in practice and make suggestions for how it can be improved.

Applying for ESA

When you apply for ESA you are normally sent a form to fill in called the ESA 50. When we asked people about the form 58% said that it was either difficult or very difficult to complete. If people find the form hard to complete then they may not give all the information needed for the government to decide if they should get ESA.

The government needs to work with disabled people to produce an improved application form for ESA.

Going for a medical assessment

Most people applying for ESA have to go for a medical assessment with an independent doctor or nurse. The government pays a company called Atos Healthcare to do these assessments.

Of those respondents who had a medical assessment nearly 79% agreed or strongly agreed that it was stressful and 69% said it actually made their health condition or impairment worse because of the stress and anxiety caused.

“Essentially on a bad day I’m house-bound as I can’t walk anywhere without experiencing fatigue, dizziness, etc. But none of this was reflected in the report. The tick boxes they go through don’t seem to be at all related to whether I can realistically sustain any sort of work. The stressful situation is starting to badly affect my physical condition.”

The assessment is meant to find out how someone’s impairment or health condition affects their ability to work. However, fewer than one in five (19%) of those respondents who had had a medical felt that the healthcare professional understood their impairment or health condition and fewer than a third agreed that the healthcare professional who carried out their assessment asked about all the symptoms/aspects of their impairment or health condition that affect their capability to work.

Of those people who had seen a copy of the report that the doctor or nurse wrote about their medical over half felt it was not an accurate reflection of the answers they had provided.

“The Atos report was full of inaccuracies and contradictions! Large areas of my symptoms went ignored – particularly the fatigue. Because I’d managed to get to the medical, they assumed there couldn’t have been any fatigue. Obviously, they didn’t see me curled up on the sofa for the next 2 days...There was also no mention of my problems with speech, cognition, fine motor control, swallowing, dizziness, joint pain etc.”

Building on an abundance of evidence already available,⁸ our results provide a clear indication that the current ESA assessment is not fit for purpose. It fails to provide the accurate and comprehensive picture of the barriers to work that a claimant may face which is needed for a fair decision as to whether or not someone should get the additional support provided by ESA.

The government needs to urgently review how assessments for ESA are carried out.

The test used for ESA

A test called the Work Capability Assessment (WCA) is used to work out who gets ESA and which of the two groups they should be in, the Support Group or the Work Related Activity Group.

⁸ Citizens Advice (2010) Not working: CAB evidence on the ESA work capability assessment, Citizens Advice, http://www.citizensadvice.org.uk/not_working; Barnes H, et al (2010) Employment and support allowance: early implementation experiences of customers and staff, Department for Work and Pensions <http://research.dwp.gov.uk/asd/asd5/rports2009-2010/rrep631.pdf>; Professor Malcolm Harrington (2010) An Independent Review of the Work Capability Assessment <http://www.dwp.gov.uk/policy/welfare-reform/employment-and-support/wca-independent-review>

The WCA has a list of criteria called “descriptors”. Each descriptor is split into several parts and each of these is worth a different amount of points. To receive ESA you have to get 15 points either on one descriptor or across several descriptors. For example, below is the current descriptor for walking.

Walking with a walking stick or other aid if such aid is normally used

- (a) Cannot walk at all (15 points)
- (b) Cannot walk more than 50 metres on level ground without repeatedly stopping or severe discomfort (15 points)
- (c) Cannot walk up or down two steps even with the support of a handrail (15 points)
- (d) Cannot walk more than 100 metres on level ground without stopping or severe discomfort (9 points)
- (e) Cannot walk more than 200 metres on level ground without stopping or severe discomfort (6 points)
- (f) None of the above apply (0 points)

Memory and concentration

- (a) On a daily basis, forgets or loses concentration to such an extent that overall day-to-day life cannot be successfully managed without receiving verbal prompting, given by someone else in the claimant’s presence (15 points)
- (b) For the majority of the time, forgets or loses concentration to such an extent that overall day-to-day life cannot be successfully managed without receiving verbal prompting, given by someone else in the claimant’s presence (9 points)

- (c) Frequently forgets or loses concentration to such an extent that overall day-to-day life can only be successfully managed with pre-planning, such as making a daily written list of all tasks forming part of daily life that are to be completed (6 points)
- (d) None of the above apply (0 points)

When the WCA was written the government predicted that 51% of those assessed would not get ESA.⁹ However, in reality 65% who complete the WCA are being turned down for ESA.¹⁰ There are serious concerns among claimants, organisations, and even among the Department for Work and Pensions (DWP) own staff that the WCA is too tough.¹¹ There are particular concerns that the criteria used do not measure fluctuating conditions. The DBC survey found that nearly 70% disagreed or strongly disagreed that the assessment took account of how their symptoms/aspects of their impairment or health condition change/fluctuate.

However, the government now plans to make the test even harder by introducing a new version of it. When this new test comes in, the government expects that of those who complete it, an estimated extra 5% of people will not get ESA (this represents 72% of those assessed

⁹ Department for Work and Pensions (2007) Transformation of the personal capability assessment, Department for Work and Pensions, <http://www.dwp.gov.uk/docs/tpca-1.pdf>

¹⁰ Department for Work and Pensions (2011) Employment and support allowance: work capability assessment by health condition and functional impairment: official statistics, Department for Work and Pensions, http://research.dwp.gov.uk/asd/workingage/esa_wca/esa_wca_25012011.pdf

¹¹ Barnes H, et al (2010) Employment and support allowance: early implementation experiences of customers and staff, Department for Work and Pensions <http://research.dwp.gov.uk/asd/asd5/rports2009-2010/rrep631.pdf>

by the WCA).¹² This is a 41% increase in the disallowance rate since the original prediction of 51%.

Before over one million people currently on Incapacity Benefit are reassessed, the government urgently needs to review the WCA, focusing on how effectively it measures limited capability for work.

The government should introduce a revised WCA that more accurately measures the impact of an individual's impairment on their ability to work

What if the government get it wrong?

If you are told you will not get ESA but you don't agree with the decision, you can appeal, and because the WCA is so tough lots of people are appealing. Over half (52.9%) of the people who completed the DBC survey who had received a decision on their application for ESA didn't agree with the decision and of these, half planned to appeal.

This is supported by data from the government. Information is only available for appeals heard (rather than appeals lodged) but from the introduction of ESA in October 2008 to November 2009 (the latest date for which appeals information is available) 33% of all those turned down for ESA have had an appeal heard, totalling 90,300 appeals and this figure can be expected to rise dramatically as people currently getting Incapacity Benefit are reassessed for ESA. Of those appeals heard, 4 in

¹² Department for Work and Pensions (2011) Employment and support allowance (limited capability for work and limited capability for work-related activity) (Amendment) Regulations Impact Assessment <http://www.dwp.gov.uk/docs/wca-ia-eia.pdf>

every 10 are successful with the tribunal saying that the original decision was wrong and the person applying should get ESA.¹³

The government must work to get more decisions right first time and it must also be open about how long people have to wait to have their appeal heard.

The government should publish the number of appeals lodged and average waiting times for appeal hearings when releasing ESA statistics.

Different types of ESA

People can either receive ESA on the basis of their National Insurance contributions (contributory ESA) or because they (including anyone they live with) are on a low income (income-related ESA). The government now plans to only pay contributory ESA to people in the work related activity group for one year. After a year, if they are on a low income they will still get ESA, otherwise their benefit will stop.

The DBC survey found that of those not in work 57% have been unemployed for two years or longer. Of this group 1 in 5 are on Incapacity Benefit (which is being replaced by contributory ESA) and therefore in the future could expect to lose their benefit, despite half saying that their impairment or health condition means they cannot work at all.

¹³ Department for Work and Pensions (2011) Employment and support allowance: work capability assessment by health condition and functional impairment: official statistics, Department for Work and Pensions, http://research.dwp.gov.uk/asd/workingage/esa_wca/esa_wca_25012011.pdf

Cutting contributory ESA after just one year penalises people for working and building up savings. If they have a partner who works, meaning they don't qualify for income-related ESA, they may be better off financially if their partner stops working so they qualify for benefits. It sets an unrealistic and arbitrary deadline for people who face major barriers to work to find a job before all support is withdrawn.

Access to contributory ESA should not be time limited.

SUPPORT FOR PEOPLE ON A LOW INCOME

The Government is introducing a new benefit for people on a low income. Universal Credit is meant to make the benefits system simpler. Rather than having different benefits withdrawn at different rates as you move into work or work more hours, you will have one fixed rate at which your benefit is withdrawn.

Universal Credit will replace existing in and out of work benefits (income-related ESA, income-based JSA, housing benefit, council tax benefit, working tax credit and child tax credit) for people on a low income.

The government is currently proposing that for people on Universal Credit, after an initial personal disregard (like the personal allowance in the tax system) you will keep 35 pence in every pound you earn until you earn enough to not need any support from the government.

Universal Credit is meant to make it easier for people on benefits to work, or work more hours, as it will be easier to know how much better

off you will be for each hour of work you do. However, we asked those people who replied to the DBC survey who are in work if they felt that if they worked more hours they would be worse off or no better off due to the loss of benefits and only 2.5% agreed. In contrast, 1 in 5 of the same group said that their impairment or health condition meant that they could not work more hours. We asked the same questions to those not in work and just under 1 in 10 said that they felt that if they work they will have less money, or the same amount of money, because of the loss of benefits. This suggests that it is not concerns about benefits that stop disabled people working or working more hours, rather the impact of their impairment.

Universal Credit must recognise that concerns about money are not the main reasons that stop people working.

Will people be better off with Universal Credit?

Some people will be better off under Universal Credit. However, there are some people that could be worse off.

Enhanced disability premium

At the moment someone who is:

- claiming a means tested benefit;
- in the ESA Support Group, or
- is receiving Disability Living Allowance highest rate care,

receives the enhanced disability premium which is currently worth £13.65 per week for a single person.

The enhanced disability premium aims to help meet the extra costs associated with disability for people with the highest needs.

The severe disability premium

At the moment someone who is:

- claiming a means tested benefit, and
- claiming DLA care at the middle or highest rate, and
- living alone,
- with no one claiming carer's allowance for providing care,

receives the severe disability premium which is currently worth £53.65 per week for a single person.

SDP is important because people living alone with no one caring for them face a wide range of extra costs, for example, needing to buy ready made meals if they are not able to prepare food or paying for help with household tasks.

The government has not decided what will happen to the enhanced disability premium or severe disability premium when they introduce Universal Credit even though they provide vital financial support to a group receiving very little help from elsewhere.

The enhanced disability premium and severe disability premium should be retained in the Universal Credit, supporting the same group of people as in the current system.

Moving into work

At the moment, disabled people who work more than 16 hours a week and have been receiving Incapacity Benefit/ESA or receive DLA get Working Tax Credit (WTC).

Under Universal Credit this will be different. Instead of getting a top up on your earnings, you will have a larger “personal allowance” called the disability disregard. This means that disabled people will be able to earn more than non-disabled people before their benefit starts to be slowly withdrawn.

The problem is in deciding who gets the disability disregard. As the government introduces an even tougher test for ESA and as changes are made to Disability Living Allowance, in the future fewer disabled people will get the benefits needed at the moment to qualify for Working Tax Credit and likely to be needed to receive the disability disregard. Disabled people face many additional barriers in accessing the workplace and WTC helps address some of these. It is important that this is recognised in Universal Credit and disabled people are not penalised because they don't get the right benefit.

The current support available to disabled people in work through the disability element of Working Tax Credit must be included in the Universal Credit.

HELP WITH EXTRA COSTS

Disability Living Allowance (DLA) is the benefit paid to disabled people to help meet the extra costs associated with disability. There are two DLA components, care and mobility. The care component is paid at three different rates, with the highest rate worth £71.40 a week whilst mobility component is paid at two different rates with the highest rate worth £49.85 a week.

Disabled people have average additional costs of 25% as a result of their impairment and DLA helps meet these costs.¹⁴ It meets a wide range of needs and the Disability Alliance survey asked respondents to state what they use DLA for and if it helps meet all their disability-related costs.

Whilst 85% of respondents recognised the contribution DLA makes to avoiding poverty, fewer than 10% said that DLA covered all their disability-related costs and 22% said that they never received enough DLA to meet their health/impairment related costs.

When DLA was introduced in 1992, the average disability-related expenditure for disabled adults was recorded as being between £4.55 and £12.53 per week¹⁵. However, in Disability Alliance's survey, disabled people report far higher average costs:

¹⁴ Parckar, G. (2008) Disability Poverty in the UK, Leonard Cheshire Disability
<http://www.lcdisability.org/?lid=6386>

¹⁵ *The Way Ahead: Benefits for disabled people* HMSO, 1990

- Just 2% of respondents believe their disability related expenditure is £20 or less per week; but the lowest DLA rates are £18.95 a week;
- Just 16% of respondents suggest their costs are £50 or less per week; this equates to middle rate care or higher rate mobility DLA rates;
- Under a third (28%) suggest disability-related expenditure is at or under the average DLA weekly payment of £70 per week;
- A quarter (26%) of respondents suggested their disability-related expenditure was over £100 per week, including almost 10% stating their higher cost of living as over £150 per week.

The main things people responding to the Disability Alliance survey said their DLA helps with are:

- transport: 89%
- heating/laundry bills: 68%
- attending medical appointments: 58%
- aids and equipment: 58%
- home help: 49%
- replacing furniture/household goods: 39%
- leisure costs: 37%
- home adaptations: 31%
- special diet: 28%
- special clothing: 25%

“I suffer from bipolar disorder and often become very paranoid and sometimes suicidally depressed. I spend a lot of my DLA on my phone and internet bills because I need a lot of reassurance from family and friends who can't be there in person. Without those long phonecalls I would be at much greater risk of harm. I spend more time than most people in my home because I am not fit to work most of the time, so DLA is useful for extra heating costs. Also, when I am very paranoid, I am unable to use public transport. DLA pays for taxis to appointments or to get shopping. If I did not get DLA, I would live in fear of getting into financial difficulty, which would make my illness worse. I spent two years in hospital. I have now managed to stay out of inpatient services for most of the past 18 months, but I am sure that without the boost DLA gives me, I would have cost the NHS much more during that time. If I lose it - which I fear I will - I have no doubt that my mental health will deteriorate.”

Changes to DLA

In the June Budget 2010 the government announced plans to reform DLA by introducing a new assessment and by 2014/15 reducing planned expenditure on the benefit by £1 billion.¹⁶ They are planning to replace DLA with a new benefit called Personal Independence Payment (PIP). As our findings show, DLA provides vital support to the 1.8 million working age people currently claiming it and it is imperative that reform is focused on meeting their needs.

¹⁶ June Budget 2010 http://www.hm-treasury.gov.uk/d/junebudget_complete.pdf

Personal Independence Payment will have two components, the mobility component (which will be awarded on the basis of an individual's ability to get around) and the daily living component (which will be awarded on the basis of an individual's ability to carry out key activities necessary to be able to participate in daily life) and both of these will be paid at two rates.¹⁷

The government has said it wants to replace DLA because:¹⁸

- “Caseload and expenditure is increasing at a rate never envisaged”
- “The current system is too complex and the benefit is not understood”
- “There is no system to check that awards remain correct”
- “The benefit can act as a barrier to work”

Even factoring in receipt of DLA, disabled people are twice as likely to live in poverty as non-disabled people and without DLA disability poverty levels would be significantly higher.¹⁹ If the increase in the number of people claiming DLA is helping reduce the number of people living in poverty, this should be seen as a good thing, not a reason to reform the benefit.

¹⁷ Department for Work and Pensions (2010) Public consultation: Disability Living Allowance reform, <http://www.dwp.gov.uk/docs/dla-reform-consultation.pdf>

¹⁸ Department for Work and Pensions (2010) Public consultation: Disability Living Allowance reform <http://www.dwp.gov.uk/docs/dla-reform-consultation.pdf>

¹⁹ Parckar, G. (2008) Disability Poverty in the UK, Leonard Cheshire Disability <http://www.lcdisability.org/?lid=6386>

The other issues could all be addressed by better communication by the DWP to make individuals more aware of their benefit entitlement and the purpose of DLA, and changes to how benefit payments are reviewed.

Therefore, whilst the government has said it plans to go ahead with plans to introduce PIP, it is worrying that money is being spent introducing a new benefit when the same goals could be achieved by reforming the existing benefit.

How will the government decide who gets PIP?

There will be a new assessment for PIP and this will be different to the assessment for DLA. This new assessment is likely to include a 'face to face' assessment with an independent healthcare professional. This assessment will have a huge impact on the lives of disabled people and it is important that as many disabled people as possible are involved in designing it.

There should be a full consultation on the assessment for PIP and the new assessment should be fully piloted before it is introduced.

How often will people have to be assessed for PIP?

The government wants people on PIP to be tested again at regular points to make sure they can still get PIP. Sometimes a person's impairment or condition can change and it is useful to check again how much benefit they should be receiving. However, to retest people with lifelong impairments that will not change is a waste of money and creates unnecessary stress for the people involved.

People should only be retested for PIP when it can reasonably be expected that their impairment or condition will change over time.

Should some people always get DLA/PIP?

Disabled people with certain impairments, where they meet strict criteria, automatically qualify for the certain rates of DLA. This is because their impairment means that they will always meet the eligibility threshold for the benefit so it would not make sense to assess them.

PIP will not have any “automatic entitlements”. However, if it is clear that certain impairments will always meet the criteria for PIP then PIP should include automatic entitlements in these cases, as they provide an easy way of awarding benefit to people who are certain to qualify and mean money is not wasted on assessments that could be spent on supporting disabled people.

PIP should include automatic entitlements for those cases where an individual’s impairment means they will always meet the criteria for the benefit.

How long does someone have to wait to get DLA/PIP?

At the moment you have to have had your impairment or illness for three months and expect to have it for at least another six months to get DLA. However, the government wants people to wait six months before they can get PIP.

The three month waiting period already makes it hard for people to adjust to their condition or impairment. People have extra costs right

from the start of the onset of their condition or impairment, for example the need for mobility aids, and making people wait even longer will push more people into debt.

Disabled people should not have to wait 6 months before they can access PIP.

What about people getting DLA at the moment?

Working age people who get DLA at the moment will be assessed for PIP from 2013. Many people are already worried that they may not get the new benefit or will be left worse off.

The government should guarantee that no one currently receiving DLA is left worse off by the introduction of PIP.

The government has not decided what will happen to DLA for children and for people over 65 (who started claiming before 65). At the moment these groups will keep getting DLA, but people are worried about what will happen in the future. The needs and extra costs of children and older people are different to those of working age disabled people.

There must be a full consultation before introducing any measures to extend PIP to non-working age recipients.

What about carers?

Under DLA a carer can get Carer's Allowance if the person they are caring for gets the middle or highest rate of DLA care. Carer's Allowance is paid at just £53.90 for 35 hours or more a week spent caring and

many people are worse off financially as a result of caring. Many carers are worried about what will happen when PIP comes in and how this might change the rules for Carer's Allowance. The loss of Carer's Allowance would have a devastating impact on carers and those they support.

Both rates of the daily living component of PIP must establish entitlement for Carer's Allowance.

DLA/PIP mobility component for people living in residential care

DLA mobility, which PIP mobility will replace, gives disabled people the power to decide for themselves how their needs should be met and provides the freedom and independence most people take for granted.

However, the Welfare Reform Bill will give the government the power to remove PIP mobility from disabled people living in residential care. If this goes ahead it will mean that many disabled people will no longer have the money to meet mobility-related costs such as powered wheelchairs, adapted cars or paying for taxis where there is no accessible public transport.

"I have an adapted car that allows me to go out as and when I want.

I use the car for all sorts of things. I love shopping, going out for meals, to the theatre, visiting my friends and family, going to the Wetland Centre or just driving into the countryside to enjoy the fresh air.

I cannot go by public transport.

If the mobility allowance is cut then I will not be able to run my car. I will not be able to afford the mileage I will be stuck. I will have no choices.

I am unable to work but I would if I could.

I can't help the fact that I am disabled - I didn't choose to be.

People living in local authority funded residential care already have most of their income taken to pay for their care and are left with just over £20 a week. If they stop getting PIP mobility there is no extra money to meet their mobility needs and people will be left trapped at home.

This policy will also impact on families, where a young person is away at college, as the loss of benefit during term time will make it impossible for the family to run an adapted car, making trips at weekends and in holidays impossible. Families with younger children are already worried about what will happen if PIP is extended to children.

DLA/PIP mobility should continue to be paid to people living in residential care.

If the government wants to look at the issue in more detail there should be an independent review of funding for personal mobility as any other option will leave disabled people worried that the government has already made up its mind.

Any review of funding for personal mobility must be independent.

CONCLUSION

The changes currently taking place to disability benefits are going to have a massive impact on the lives of millions of disabled people.

The DBC survey findings show how difficult many people are finding the application process for Employment and Support Allowance and as over one million Incapacity Benefit claimants undergo the new test many more can be expected to experience the stress and anxiety reported by respondents.

For many people it will be a double blow as the government plans to start reassessing people currently getting Disability Living Allowance for the new benefit, Personal Independence Payment, from 2013. Our findings show how vital the support offered by DLA is and already disabled people are worried about what PIP will offer and about what they will do if their support is reduced. One group particularly concerned are people in residential care currently receiving DLA mobility component who face being trapped in their homes if the government stops paying this vital benefit to them as they introduce PIP.

Reform of disability benefits is placing immense pressure on disabled people and it is important that as changes are made, these are designed in partnership with disabled people and are aimed at meeting individuals' needs, not reducing costs.

At the moment the support offered to disabled people through the benefits system is shrinking and fewer and fewer people are receiving the support they need.

RECOMMENDATIONS

Employment and Support Allowance

- The government needs to work with disabled people to produce an improved application form for ESA.
- The government needs to urgently review how assessments for ESA are carried out.
- The government should introduce a revised WCA that more accurately measures the impact of an individual's impairment on their ability to work.
- The government should publish the number of appeals lodged and average waiting times for appeal hearings when releasing ESA statistics.
- Access to contributory ESA should not be time limited.

Universal Credit

- Universal Credit must recognise that it is not concerns about money that stop people working.
- The enhanced disability premium and severe disability premium should be retained in the Universal Credit, supporting the same group of people as in the current system.
- The current support available to disabled people in work though the disability element of Working Tax Credit must be included in the Universal Credit.

Disability Living Allowance (DLA) / Personal independence Payment (PIP)

- There should be a full consultation on the assessment for PIP.
- The new assessment should be fully piloted before it is introduced.
- People should only be retested for PIP when it can reasonably be expected that their impairment or condition will change over time.
- PIP should include automatic entitlements for those cases where an individual's impairment means they will always meet the criteria for the benefit.
- Disabled people should not have to wait 6 months before they can access PIP.
- The government should guarantee that no one currently receiving DLA is left worse off by the introduction of PIP.
- There must be a full consultation before introducing any measures to extend PIP to non-working age recipients.
- Both rates of the daily living component of PIP must establish entitlement for Carer's Allowance.
- DLA/PIP mobility component should continue to be paid to people living in residential care and schools.
- Any review of funding for personal mobility must be independent.

GLOSSARY

Carer's Allowance is paid to individual's spending 35 hours a week or more caring for someone who gets Disability Living Allowance care component at either the middle or highest rate.

Department for Work and Pensions is the government department responsible for benefits like Jobseeker's Allowance, Employment and Support Allowance, Disability Living Allowance and Carer's Allowance.

Employment and Support Allowance (ESA) is the benefit for people unable to work due to ill health or disability. People on ESA are either in the Work Related Activity Group where they receive a lower rate of benefit and have to do things aimed at preparing them for work or the Support Group where they receive a higher rate of ESA and do not have to do anything in return for their benefit.

Disability Living Allowance (DLA) is the benefit paid to disabled people to help meet the extra costs associated with disability. There are two DLA components, care and mobility. The care component is paid at three different rates, with the highest rate worth £71.40 a week whilst mobility component is paid at two different rates with the highest rate worth £49.85 a week.

Enhanced Disability Premium is paid to disabled people claiming a means tested benefit who are either in the ESA Support Group or receiving Disability Living Allowance highest rate care,

Jobseeker's Allowance (JSA) is the main out of work benefit for working age people and in return for their benefit claimants have to show that they are trying to get a job.

Personal Independence Payment (PIP) will replace Disability Living Allowance as the benefit designed to meet the extra costs associated with disability. There will be two components, mobility and daily living, and both of these will be paid at two different rates.

Severe Disability Premium (SDP) is paid to disabled people claiming a means tested benefit, living alone, receiving DLA care at the middle or highest rate with no one claiming carer's allowance for caring for them.

Universal Credit will replace existing in and out of work benefits (income-related ESA, income-based JSA, housing benefit, council tax benefit, working tax credit and child tax credit) for people on a low income.

Work Capability Assessment (WCA) is the test used to work out who gets ESA and which of the two groups, the support group and the work related activity group they should be in.

FURTHER INFORMATION

If you would like any further information please contact:

Rebecca Rennison

Co-chair DBC policy group

Senior Policy Officer, Leonard Cheshire Disability

E: rebecca.rennison@lcdisability.org

T: 020 3242 0269

A: 66 South Lambeth Road, London, SW8 1RL