

# **End of a lifeline?**

**Ending Disability Living Allowance to  
introduce Personal Independence Payment**

**DLA reform consultation response**

**Disability Rights Partnership**

**February 2011**

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## **The Disability Rights Partnership and this response**

Disability Alliance produced this response for the 'Disability Rights Partnership' which is the working title for the unification of Disability Alliance, the National Centre for Independent Living and Radar.

Our organisations are led by disabled people. Between us we represent over 500 local and national organisations. Our response has been developed in consultation with our members and through our wider research of disabled people, carers and advisors' views on the Government proposals.

Over 1,700 people completed our survey and 82% were receiving or caring for someone using DLA<sup>1</sup>. This represents a significant piece of DLA research and provides a strong evidence base for our consultation response.

**We are very grateful to our members and all the individuals who have taken the time to contribute to our response.**

**Disability Alliance:** is a UK charity and aims to break the link between poverty and disability. We have over 250 members and 36 years of benefits and welfare experience. See: [www.disabilityalliance.org](http://www.disabilityalliance.org)

**The National Centre for Independent Living (NCIL):** is a national support, advice and consultancy organisation that aims to enable disabled people to be equal citizens with choice, control, rights and full economic, social and cultural lives. See: [www.ncil.org.uk](http://www.ncil.org.uk)

**Radar:** The Royal Association for Disability Rights (Radar) is a pan-disability organisation led by people with lived experience of disability or health conditions. Radar's vision is a just and equal society whose strength is human difference. Radar's mission is to enable individuals, networks and policy-makers to do things differently – and better. See: [www.radar.org.uk](http://www.radar.org.uk)

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<sup>1</sup> See: [www.disabilityalliance.org/dlatest.htm](http://www.disabilityalliance.org/dlatest.htm) for further details on the survey. See Appendix A for information on the survey respondents.

## Summary

We welcome reforms which seek to improve access to welfare support and the efficiency and effectiveness of services for disabled people. In 2009 we proposed reforming DLA to tackle bureaucracy, raise awareness of support and help meet the genuine costs of living experienced by disabled people<sup>2</sup>.

But the Government proposals are underpinned by an unexplained<sup>3</sup> target of cutting DLA expenditure by 20% by 2015/16. The proposals also represent a potential shift from the original purposes of DLA which was introduced to help disabled people with higher costs of living and support disabled people who did not have the highest levels of needs.

**We believe the new approach risks over 835,000 disabled people losing what is often described as an essential 'lifeline' of support.**

The main overall findings from the respondents to our survey were that:

- 9% (of 900 responses) said losing DLA may make life not worth living;
- 16% suggested cuts to DLA will result in higher use or costs to the NHS, with 14% suggesting a likely need for more local council services;
- 27% of the DLA recipients were in work but more than half (56%) say they would have to stop or reduce work if they lost access to support;
- Almost two thirds (62%) highlighted the link from DLA to other support and fear reform will cut the link and increase exclusion and poverty – with 35% reporting finding it difficult or very difficult to get by already;
- Less than 10% stated that DLA covered all their disability-related costs and DLA is most commonly used to contribute towards disabled people's non-luxury items like transport (89%), heating/laundry (68%) and aids/equipment (58%).

Despite the significant impact of reform on so many disabled people and their families, the Government approach has been severely flawed. The Welfare Reform Bill which will abolish DLA was published before the DLA consultation closed. The Government's timeframe has prevented adequate analysis of the impact of proposals, including through the involvement of disabled people.

Disabled people and their families believed the Conservative Party would retain its manifesto commitment to 'protect' DLA<sup>4</sup>. There is considerable surprise and disappointment with the speed and potential level of withdrawal of DLA under the coalition Government.

<sup>2</sup> See: *Tackling Disability Poverty* Disability Alliance, 2009 - supported by 17 national organisations.

<sup>3</sup> Despite requests, neither the DWP nor Treasury have detailed how the 20% cut was devised.

<sup>4</sup> *Invitation to join the Government of Britain* Conservative Party Manifesto, April 2010. The pledge arose partly in response to the previous Government's proposal to place DLA resources into local authority administered social care budgets.

The reform consultation also contained significant inaccuracies and the Department for Work and Pensions (DWP) has had to correct statements on the numbers of disabled people affected and the overall objective of reform. Our survey respondents expressed strong anxieties over the perceived unfairness of the plans and significant concerns that the full impact of proposals had not been fully understood by Government.

### **Analysing the full costs of proposals**

We believe that the potential costs to governments of the reform proposals must be better analysed, including:

- Costs to the NHS through avoidable hospitalisation or treatment of people unable to manage conditions without (or with reduced) DLA;
- Costs to councils from disabled people developing higher needs and requiring (greater) social care or other support (eg housing); and
- Costs to the Treasury through lost or reduced income tax and National Insurance contributions from disabled people and carers unable to maintain current levels of employment or take-up work.

Disabled people's fears of the impact of the Government proposals must also be addressed. Fears are based on disabled people's current situation; a third of disabled people already live in poverty with DLA representing an essential lifeline. The following (verbatim) quotes expose the risks to healthcare, social services, work opportunities and disabled people's lives in very human terms:

- 'my illness will get stronger and i would eventually...be put back in my mental health hospital again for my own well being'
- 'I think...his mental and physical health would deteriorate. I have no doubt he would end up back in psychiatric hospital'
- 'We would struggle to manage. Our son would probably have to go into residential care'
- 'I, as a carer, would need to give up work'
- 'I would not be able to survive without DLA'
- 'I think that I would just lose the will to live'
- 'When that happens I hope I would have the courage to die'
- 'DLA makes the difference between having a tiny little bit of independance and life not being worth living'
- 'My DLA has allready been reviewed in 2009...I went through 5 months of extreme anxiety and worry during the review, resulting in a deterioration of my allready very fragile health...My health condition is chronic and there is no cure, if my DLA was reviewed again I don't think I would have the will to live anymore'

Failing to ensure the implications of the proposals are fully understood risks catastrophic consequences for disabled people and their families. It also risks significant additional demand on both the NHS and local councils at a time of considerable expenditure constraints across public services.

Disability organisations would welcome a greater partnership role with Government to ensure the risks disabled people have identified in our survey are addressed in reform proposals and through the new assessment.

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## **Background/purpose of DLA and the Government proposals**

Our response contains numbers that appear in square brackets, eg [2]. These numbers refer to the question numbers in the consultation document. We try to use them once in any section or sub-section rather than every sentence where they might be relevant, but the response should be read in its entirety in any case. Many questions overlap and many of the issues we raise below have relevance to multiple questions posed in the consultation. A list of the consultation questions is provided as Appendix B for ease of reference.

We welcome positive indications in the consultation, including emphasising benefit and support simplification [9]. We believe efforts to reduce the oft-reported disabled people's feeling of being 'over-assessed' in order to access support could have been welcome. But we are very concerned that the desire to simplify benefit access has led the DWP to shift from a current self-assessment based process to a £675 million, more 'bureaucratic' approach of requiring further forms to be completed, potential multiple face to face interviews to be attended, increased medical evidence to be sought and a substantial increase in DWP staff contact (with a resultant time and resource impact) through additional reporting and review requirements.

If the PIP assessment is as ineffective as the equivalent Work Capability Assessment for out of work benefits in identifying disabled people's needs it is likely to also result in large numbers of expensive appeals (see page 29 for further information on the WCA). It is difficult to understand or accept the premise for additional expenditure on bureaucracy at a time of significant cuts to disabled people's support.

## **Purpose of DLA/the PIP**

Overall, we are disappointed at the general level of detail in the consultation and announcements on DLA reform to date. The Government has created anxiety for many disabled people and their families. We seek significant further clarification on the following issues of concern in particular:

1. How disabled people's higher costs of living which result from health conditions/impairments will be taken into account in the new PIP assessment process; and
2. How disabled people unable to access alternative formal support or services will be able to access the PIP.

These two issues were at the core of the rationale for introducing DLA and the Minister for Disabled People, Maria Miller MP, suggests at least one remains; that the Government is:

“steadfast in our support for the principles of DLA, as a non-means-tested cash benefit contributing to the extra costs incurred by disabled people”<sup>5</sup>.

However, the proposals for the new PIP assessment do not appear to take into account extra disabled people's higher costs – and the future of people with lower level needs is even more uncertain [22].

### **From Disability Living Allowance**

The full components and rates for DLA and further background information about how the benefit works can be found on the Disability Alliance website<sup>6</sup>.

DLA was announced in ‘The Way Ahead: Benefits for disabled people’ in 1990 by the last Conservative Government<sup>7</sup>. DLA was designed to help with:

“income loss related to disability and the extra costs that flow from it”.

Disabled people's higher costs of living remain relevant today [1]; as does the low employment rate of disabled people with under half working age disabled adults in jobs<sup>8</sup>. This is after a long period of sustained growth and disabled people may be at greater risk of losing employment in the current economic climate and government expenditure cuts as disabled people are disproportionately represented in the public sector<sup>9</sup>.

With eleven candidates available for every one job currently advertised<sup>10</sup>, the employment market also weakens disabled people's opportunities – especially when high levels of employer discrimination are taken into account in recruitment processes and attitudes for example<sup>11</sup>. This decreases disabled people's earning potential even in 2011; after more than a decade of

<sup>5</sup> *Disability Living Allowance reform* DWP, 2010, Ministerial foreword.

<sup>6</sup> For an explanation of current DLA rates and how they are applied see: [www.disabilityalliance.org/f23.htm](http://www.disabilityalliance.org/f23.htm)

<sup>7</sup> *The Way Ahead: Benefits for disabled people* HMSO, January 1990.

<sup>8</sup> *Disability Briefing March 2006* Disability Rights Commission, 2006.

<sup>9</sup> For 2004 research on disabled people and public sector employment see: <http://www.leeds.ac.uk/disability-studies/archiveuk/Thornton/Employment%20summary.pdf>

<sup>10</sup> *Working Brief* Centre for Economic and Social Inclusion, January 2011.

<sup>11</sup> People with mental health problems face particularly high levels of employer discrimination. See: [http://www.mind.org.uk/news/252\\_employers\\_must\\_work\\_on\\_mental\\_health](http://www.mind.org.uk/news/252_employers_must_work_on_mental_health)

Disability Discrimination Act protection the playing field is still not level. Disabled people in work also earn less<sup>12</sup>, making DLA help with in-work support even more crucial (eg to help cover higher transport costs for using an accessible private vehicle or taxi).

But DLA was also designed to address challenges identified in significant research which discovered that disabled people most in need of help with the extra costs of living resulting from an impairment/health condition were people who often failed to qualify for alternative support. *The Way Ahead* proposed that DLA would:

‘introduce new lower rate payments for people with care and mobility needs lower down the severity scale.’

Whilst the numbers of disabled people receiving DLA have exceeded the 1990 predictions, it is important to emphasise that medical advances and our changing demographics have seen rising numbers of disabled people in the general population – including people with low level needs who remain outside of other services but experience high disability-related costs of living.

### **To the Personal Independence Payment**

We are very concerned over how disabled people’s higher costs of living are planned to be taken into account in the proposed assessment for the Personal Independence Payment. The consultation states that the Government is:

‘committed to maintaining an extra-costs, non-means-tested disability benefit.’

But it is unclear from the consultation process [3] how costs will be factored into the assessment; with one question asking what the main extra costs are despite significant research and evidence on the issue, including that undertaken by DWP<sup>13</sup>.

In meetings with the Minister and DWP officials it has remained unclear as to how costs are being considered – if at all. In questions to DWP about how costs would be analysed as part of any assessment, the reply received stated that DWP is:

“planning to assess an individual’s ability to carry out everyday activities and participate in society”.

This is very disappointing and undermines the Government’s aim of maintaining an extra-costs benefit. We do not expect DWP to assess

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<sup>12</sup> *Disability Briefing March 2006* Disability Rights Commission, 2006.

<sup>13</sup> *Review of international evidence on the cost of disability* DWP, 2008.



individuals' daily spending but the higher costs should form a part of the assessment process. We believe it is essential for the Government to urgently ensure disabled people's essential and higher costs of living are factored into the PIP assessment process.

If the Government had announced a new assessment and improved personalisation of disability benefits alone we may have been more welcoming of proposals [9].

A personalised approach could have taken into account the positive link between involvement and health outcomes, as stated in the NHS White Paper<sup>14</sup>. This alludes to the fact that the more someone is directly involved in managing their own condition the greater the impact not just on quality of life but also on health outcomes (or at least the slower/delayed deterioration). The DWP proposed 'objective' assessment may remove this link as there is no provision for a co-produced assessment or at least a user-defined focus on outcomes, ie what people want/need to achieve with their lives. For some people this may mean that they need 2 hours or so in fresh air per day in order to get going and cope with a health condition. But 'individual circumstances' have only been included when this serves to justify reductions in PIP (eg through aids and adaptations) rather than effectively supporting disabled people to get on with life. Proposals may create and sustain the same traps which the Government seeks to tackle in welfare reform.

The underlying objective of reform has been clearly to cut expenditure by 20% by 2015/16, reducing the rates of support and failing to help with many disabled people's higher costs. These concerns far outweigh the improvements the proposed new assessment might bring.

### **The 20% cut**

The rationale for the Government plans was made clear in Parliament by the Chancellor of the Exchequer in June 2010<sup>15</sup>. The Treasury announced that working age DLA 'caseload and expenditure' would be cut by 20%. This commitment and level of cut was restated by the Minister for Disabled People in December shortly after the consultation was launched<sup>16</sup>:

“we are looking at saving 20% of the Disability Living Allowance expenditure in line with the Chancellor's commitment.”

The Welfare Reform Bill states the intention of cutting DLA expenditure by 20% by 2015/16 – estimating a total loss to disabled people of £2.1 billion<sup>17</sup>. This figure is higher than disabled people expected – previous analysis had

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<sup>14</sup> [www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_117353](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_117353)

<sup>15</sup> *Budget 2010 Policy Costings* HMT, June 2010.

<sup>16</sup> See: [www.ablemagazine.co.uk/exclusive-interview-maria-miller-mp-on-the-dla-consultation/](http://www.ablemagazine.co.uk/exclusive-interview-maria-miller-mp-on-the-dla-consultation/)

<sup>17</sup> See: <http://www.dwp.gov.uk/docs/dla-reform-wr2011-ia.pdf>

used the current level of expenditure on working age adults only and Disability Alliance used a conservative figure of £1 billion being cut with 750,000 current disabled people using DLA losing support.

We believe the Government's approach risks exacerbating the link between poverty and disability [1] and comes at a time of considerable cuts to public services which will disproportionately impact on disabled people. We believe that DLA cuts represent disabled people shouldering a disproportionately large share of the burden of tackling the national deficit [1, 21].

We have further concerns over the process for introducing the PIP and reform (see page 26 onwards). But overall, the manner of Government announcements, lack of detail, shifting figures and rationale and poor analysis of risks has led disabled people to fear that the PIP represents the 'end of the lifeline' which DLA has provided. This is in the context of broader cuts to disabled people and their families' support<sup>18</sup>.

Despite the Government's stated commitment to supporting disabled people to lead 'active and independent lives'<sup>19</sup>, we believe the changes will have a hugely detrimental effect for a significant number of disabled people and their families [1, 3] – as well as to government resources through increased need of crisis treatment and support in particular [15].

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## **Access to DLA: the evidence on needs**

The Government proposal will significantly reduce access to support [1]. This contradicts previous evidence which suggested DLA does not reach enough disabled people. The Work and Pensions Select Committee has previously emphasised the need to ensure DLA reached more disabled people:

'We have looked at Disability Living Allowance (DLA) in a number of our past reports, and have called for its level to be reviewed, and for more work to increase take-up<sup>20</sup>.

And, in 2009, Radar highlighted the £7 billion in unclaimed benefits which could also help disabled people<sup>21</sup>.

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<sup>18</sup> *Destination Unknown* Claudia Wood and Eugene Grant, Demos, 2010 estimates disabled people will lose £9 billion in support over the course of this Parliament from welfare changes – and council care service cuts will impact further on available support.

<sup>19</sup> As outlined in the consultation document on p7.

<sup>20</sup> *Tackling Pensioner Poverty* House of Commons Work & Pensions Select Committee 5<sup>th</sup> Report, July 2009.

<sup>21</sup> *Doing money differently* Radar, 2009.

In January 2011 the Pensions Minister, Professor Steve Webb MP, also highlighted the difference unclaimed means-tested benefits could make on pensioner's lives:

'Our latest estimates show that if there were 100% take-up of all means tested benefits (pension credit, housing benefit and council tax benefit) by pensioners entitled to them, the number of pensioners below 60% of contemporary median income, after housing costs, would fall by around 600,000, based on 2009-10 benefit rates.

We want to ensure that older people receive the help that they are entitled to and we are conducting a research study into the feasibility of using existing data to help to improve the take-up of pension credit.

The Pension Disability and Carers Service (PDCS) continues to work closely with local organisations to encourage and support people to take up the benefits they are entitled to. It will continue to work with local partners to reach particularly vulnerable customers who are not aware of their full entitlements, helping these customers complete application forms for the range of benefits during the one visit'.

The Minister's response relates to means-tested benefits only. Attendance Allowance (the alternative DLA benefit for people over the age of 65 when applying) is not means-tested and could help even greater numbers of older disabled people.

The equivalent is true for DLA and people under 65 years of age. But the Minister's response exposes a different approach in Government between support for people over 65 and the targeting of working age benefits for reductions (including DLA reform and the time limiting of contributions-based Employment and Support Allowance to one year<sup>22</sup>).

Sadly, working age disabled people appear to be having needs overlooked. This is despite strong support for DLA being demonstrated as recently as December 2009 by Parliament:

"this House recognises the vital support that attendance allowance and disability living allowance provide for disabled people; notes that these benefits are intended to meet the additional costs of living with an impairment or long-term health condition... welcomes the Government's announcement that disability living allowance for people under 65 years will not be scrapped".

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<sup>22</sup> For information on the ESA cuts and their impact please visit: [www.disabilityalliance.org/esacut.htm](http://www.disabilityalliance.org/esacut.htm)

This statement was made by Andrew Lansley MP just fifteen months ago<sup>23</sup>. Mr Lansley is now Secretary of State for Health but his view, shared across Parliament so recently, about the evidence on disabled people's needs and higher costs appears, in an effort to cut expenditure, to have been overlooked with potentially disastrous consequences for the Department of Health.

We provide information on how people use DLA (see page 18) but there has been speculation over the growth in DLA. This reflects growing awareness of the benefit, growing numbers of disabled people and rising costs attached to living with health conditions/impairments. We provide some information on costs and the rates of the original benefit based on 1980s research (see page 16). DLA was introduced to help disabled people with lower level needs but higher costs and in 2011 the low rate care payment remains paid at the relatively low level of £18.95 per week.

### **DLA, fraud and error**

The Government's DLA approach has been couched in the broader rationale for targeting welfare and disability benefits for significant cuts: fraud. The Chancellor, George Osborne MP, emphasised the need to pursue welfare reform due to the level of fraud in the system<sup>24</sup>. Disability organisations support action to tackle benefit fraud – especially in disability benefits where fraudulent claims influence the general public's perception of misused benefits, increase stigma attached to disability and benefits and deny some disabled people support who have genuine needs.

However, DLA does not have a track record of fraud or error. Suggesting or implying fraud acts as a deterrent to seek support – generating a barrier for disabled people and their families needing help [1]. The National Audit Office analysed benefit fraud and error in 2008<sup>25</sup> and reported that of the total fraud and error in DWP benefits (as opposed to HMRC distributed tax credits), about 0.6% of benefit expenditure was fraudulently claimed.

The DWP report on DLA specifically suggested a similar figure in 2005: 0.5% for the potential level of overpayments<sup>26</sup>. This is lower than the level of official error in DLA payments but instead of tackling inefficient waste, the DWP believe an expensive new assessment is the solution which will deliver a layer of new complexity to the process of accessing support [9].

It cannot be fair to justify a 20% cut in working age DLA expenditure on a Government statistic of 0.5-0.6% potential fraud in the system. It also seems punitive to target many disabled people for a reduction or loss in support

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<sup>23</sup> House of Commons, Hansard, 8 December 2009.

<sup>24</sup> Hansard, 20<sup>th</sup> October 2010. Although the Chancellor's estimate of 'over £5 billion' of welfare fraud appears to be based on fraud and error – which includes DWP and clerical error in overpayments.

<sup>25</sup> *Department for Work and Pensions: Progress in tackling benefit fraud* National Audit Office 2008.

<sup>26</sup> *Fraud, Error and other Incorrectness in Disability Living Allowance* DWP, 2005.

using a new bureaucratic process when the existing system's 'official error' has caused more inaccuracy than evidenced fraud.

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## **Number of people affected by Government proposals**

We believe it is important to consider who may lose out through reform but DWP are yet to publish modelling on how many people may lose DLA support. DWP has printed a table listing total DLA recipients in the Welfare Reform Bill documentation rather than working age DLA or any other more useful data or indicators of the people most at risk. We have drawn up the following estimates as the Government's plans still lack detail.

There are currently 1.8 million working age DLA recipients<sup>27</sup>. All will be affected by the Government's proposal to reassess recipients using tighter eligibility criteria, fewer rates of the new benefit and renaming DLA 'Personal Independence Payment' (PIP).

The DLA consultation also suggests the Government will reserve the power to extend the new assessment process (and therefore restrictions to PIP eligibility) to children and older people currently receiving DLA. This would extend the impact of reform to all 3.1 million people accessing DLA<sup>28</sup>.

The Welfare Reform Bill highlights that the PIP will be made automatically unavailable after people reach retirement age or 65 years of age (whichever is higher)<sup>29</sup>. This also means a reduction in support and further assessment costs. During the consultation it was not made clear that older disabled people would lose support – the only alternative to the PIP will be Attendance Allowance which does not provide mobility support.

This further cut potentially removes thousands of older disabled people from accessing essential help to maintain independence – possibly preventing family commitments being met, or work or volunteering being pursued after 65. But we do not know how much of a cut this will generate from projected DLA expenditure at this stage.

## **Cutting caseload and using average payments as an estimate**

Using the 1.8 million figure for working age recipients, a 20% cut in caseload would mean 360,000 disabled people losing support. But this level of caseload cut would not secure the £2.1 billion reduced expenditure target announced in the Welfare Reform Bill<sup>30</sup>.

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<sup>27</sup> Using the Government working age definition of people 16-64 years of age.

<sup>28</sup> DWP statistics using ONS data, May 2010.

<sup>29</sup> Part 4 of the Bill, Clause 81.

<sup>30</sup> See: <http://services.parliament.uk/bills/2010-11/welfarereform/documents.html>

Using the average weekly payment (£70) multiplied by 52 (weeks) results in £3,640 per year. The total level of cut (£2.1 billion) divided by this figure suggests 577,000 existing or new disabled claimants would need to be prevented from accessing the PIP to generate the level of reduced expenditure required.

But this simple conversion of the cut into average payments is also likely to be an underestimate, partly due to the levels of support of the people most likely to be affected.

### **An end to 'low care' support**

Many people receive lower than average DLA support rates, but the Government has committed to target PIP resources at people with the greatest needs:

“we must reform DLA to make sure we focus on those that need the greatest help to live independently”<sup>31</sup>.

The Government has proposed to end the current low rate care payments of DLA<sup>32</sup>. Currently, 643,000 disabled people of working age receive the lower rate payment of care (using the latest ONS data, available from DWP, from May 2010) [4]. Lower rate care DLA is paid at £18.95 per week which is £985.40 per person per year. The total payments of low rate care amount to £634 million per year.

Some people receiving low rate care also receive mobility payments. If the number of people receiving low rate care and any mobility payment lose access to this support also, further cuts are possible.

People on low rate care and low rate mobility payments (173,000 at £18.95 per week) and people receiving low rate care and high rate mobility payments (230,000 at £49.85 per week) losing all DLA support would result in a further £770 million from DLA/PIP expenditure being cut. This would take £1.4 billion from totally removing 643,000 disabled people from receiving any DLA/PIP support. But the Government target is over £2.1 billion to cut from DLA expenditure; still a massive shortfall.

Using the average DLA payment (£3,640 per year), Disability Alliance estimates that possibly 192,000 more people could be unable to access the PIP. Some would be new applicants but only then would the further £700 million cut from PIP expenditure reach the Government's target.

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<sup>31</sup> *Disability Living Allowance reform* DWP, 2010.

<sup>32</sup> DLA currently has lower, middle and higher rates of payments for people needing 'care' support and a lower and higher rate of payment for people requiring 'mobility' support. The PIP will have two rates of payment for each component (with 'care' being shifted to a 'daily living' rate).

## **Lower payments?**

However, DWP have not indicated whether the PIP rates for 'mobility' and 'daily living' will be paid at the same rates as existing DLA awards for care and mobility.

The Government may reduce the rates for all recipients in introducing the PIP which would affect greater numbers of people overall, but less people would lose all support than our estimates might suggest.

## **Total estimate**

It is very difficult to estimate accurately how many people could lose access to support in the proposals to end DLA and introduce the PIP. To reach the targeted reduced expenditure it seems very likely that all DLA recipients are at risk of losing some level of support – either through lower rates, reduced eligibility or direct cuts<sup>33</sup>.

Disability Alliance has estimated that the 643,000 disabled people on low rate care and any mobility payment appear to be most at risk. Including 192,000 further 'average' recipients would reach the £2.1 billion target. This suggests 835,000 working age adults would lose all DLA but the final figure is unlikely to be this high as some of the cuts will come from older people losing mobility support as they retire or turn 65 as well as from new applicants (rather than current recipients).

But this figure is not totally extreme given the high level of cuts planned and as we are excluding:

- children and older people who may be covered by the new assessment at a later date;
- the families/carers of the disabled people directly affected (losing access to Carer's Allowance for example);
- older disabled people facing the retirement age or 65 years of age cut off point from receiving the PIP; and
- the 80,000 disabled children and adults in care homes who will lose DLA mobility payments from March 2013 (see page 33).

We are unsure what the exact total will be but the estimated totals above represent cause for significant concern, not least due to disabled people's current economic situation. DWP must provide further, detailed evidence on how many people stand to lose some or all of the support currently received.

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<sup>33</sup> For an explanation of current DLA rates and how they are applied see: [www.disabilityalliance.org/f23.htm](http://www.disabilityalliance.org/f23.htm)

## Disabled people, poverty, costs of living and DLA

A third of disabled people live in poverty in the UK and disabled people are twice as likely to live in poverty as other citizens<sup>34</sup>. Reasons for poverty include unequal access to education and employment, but higher costs are also incurred through having to pay additional sums for items other citizens take for granted or do not have to pay a 'disability supplement' for, including utility bills (eg to pay for higher water bills due to increased laundry needs through incontinence) [1, 3].

Disabled people are amongst the most disadvantaged groups in the UK. Nearly a quarter of individuals in families with at least one disabled member live in relative income poverty and over 50% of working age disabled adults are not in paid employment.<sup>35</sup> A third of working age disabled people are estimated to live in poverty – and disabled people's higher living costs are unaccounted for in most tests of poverty, meaning actual poverty levels are likely to be higher [1].

Millions of disabled people also rely on financial and other support from the state to help meet their basic social care needs and the extra living costs associated with their impairment [16]. However, the Coalition on Charging and Leonard Cheshire Disability have reported on the impact of public service use on disabled people's chances of living in poverty<sup>36</sup>. Leonard Cheshire revealed that, of disabled people living in poverty and using social services provided by councils, more than half were paying for some or all their care [8, 19].

DLA was developed through 1980s research under the last Conservative Government to enable disabled people to meet evidenced higher costs of living. This has helped some disabled people avoid poverty which the current Government risks undermining [22].

### Disabled people's higher costs of living

When DLA was introduced the average 'disability-related expenditure' [1] was recorded as being between £4.55 and £12.53 per week for disabled adults (with higher levels for parents of some disabled children)<sup>37</sup>. In our 2010/2011 survey disabled people report far higher average costs, with estimates in the table below [3]:

£1-10	0.2%
£11-20	1.8%
£21-30	4.2%
£31-40	3.7%

<sup>34</sup> For further information on disability poverty see: *Tackling Disability Poverty* Disability Alliance 2009.

<sup>35</sup> [http://www.statistics.gov.uk/elmr/06\\_10/downloads/ELMR-Jun10-Barrett.pdf](http://www.statistics.gov.uk/elmr/06_10/downloads/ELMR-Jun10-Barrett.pdf)

<sup>36</sup> *Charging into Poverty?* Coalition on Charging, 2008; *Disability Review* Leonard Cheshire Disability, 2009.

<sup>37</sup> *The Way Ahead: Benefits for disabled people* HMSO, 1990.



£41-50	6.5%
£51-60	6.3%
£61-70	5.7%
£71-80	5.9%
£81-90	3.8%
£91-100	9.7%
£101-110	5.9%
£111-120	3.9%
£121-130	2.4%
£131-140	1.3%
£141-150	2.7%
£151+	9.7%

Over a quarter (26.3%) could not state their costs as often the additional expenditure is 'masked' within general bills (eg heating) and has never been directly calculated.

However, our survey reveals that [3]:

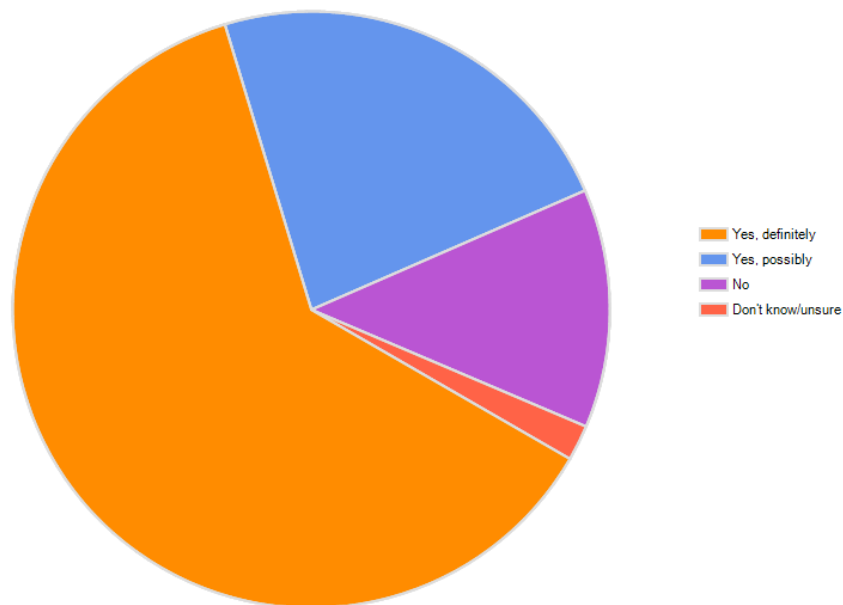
- 2% of respondents believe their disability related expenditure is £20 or less per week; but the lowest DLA rates are £18.95 a week;
- 16% of respondents suggest their costs are £50 or less per week; this equates to middle rate care or higher rate mobility DLA rates;
- under a third (28%) suggest disability-related expenditure is at or under the average DLA weekly payment of £70 per week;
- a quarter (26%) of our 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.

Several respondents used the space on our survey to highlight their costs being much higher – with estimates including some people paying over £400 and at least one declaring their weekly costs reached £1,200. The maximum payment from DLA per week would be £121.25<sup>38</sup> which would cover just 10% of the highest estimate we received.

But 85% of respondents also recognised the contribution that DLA makes towards avoiding poverty:

<sup>38</sup> DWP data suggests just over half a million people received this level of payment in May 2010.

Do you believe that DLA helps you/the person you care for/represent avoid living in poverty?



Despite recognition of the help DLA provides in helping tackle and/or avoid poverty, half our respondents (49%) stated that DLA 'did not provide enough money to live on' [3] and 22% said that they never received enough DLA to meet their health/impairment related costs.

### Use of DLA

DLA is not restricted in use [2] – it was designed to help disabled people with the full range of higher costs of living. The DWP and others have undertaken research on DLA use<sup>39</sup>. In our survey, people told us that the main items DLA helped with were:

- 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%

Many of these items are only required by disabled people [1]. But the vast majority are also essential expenditure and cannot be avoided. Some are paid for by everyone but disabled people experience an extra cost for items compared to other citizens – eg for particular diets to manage health conditions and more expensive than average water bills to cover higher laundry needs.

<sup>39</sup> *The Impact of Disability Living Allowance and Attendance Allowance: Findings from exploratory qualitative research* DWP, 2010.

Even the additional costs disabled people experience for a short break away (eg higher cost for an adapted room or the need to pay for a carer to accompany) are not luxury items and are seen as ‘disability supplements’ by some disabled people and their families.

Other items people chose to specify in answering open questions in our survey included:

- Blue Badges
- fuel (with many highlighting the need not just for a one-off payment for a car, but the need to maintain and run a vehicle);
- gym membership (to maintain health, tackle overweight issues and even use an accessible shower by one respondent);
- having food deliveries for people unable to visit a supermarket;
- carers (including paying for carers’ food and drinks when visiting the disabled persons’ home);
- prescriptions and other medical costs;
- internet and other IT costs to maintain community links;
- insurance on equipment (including vehicles);
- general home/personal care (eg haircuts and window cleaning); and
- rent and other bills (including council tax and care charges).

Using DLA flexibly was one of the original aims behind the benefit. It is welcome that the Government consultation does not include proposals to change the way PIP could be used [2]. However, significant consideration must be applied to how a new assessment will include items which disabled people use DLA for currently – especially maintaining and replacing equipment or helping to meet higher costs (such as expensive utility bills) [8].

### **The PIP and impairment type**

Half our respondents (49%) suggested the PIP should be paid based on health condition/impairment type [5, 7, 9, 10, 11, 12]. Many disabled people believe a simpler system would calculate costs based on impairment types. This is not the most sophisticated approach but has the support of many disabled people and reviews could help ascertain if people’s costs remain high [13].

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## **Potential costs of reform and affects on disabled people**

DLA reform comes amidst other public service and benefit changes which will disproportionately affect disabled people. The main ‘burden’ disabled people will directly shoulder is within the £18 billion in welfare spending cuts, including the DLA reduction and £2 billion removed from time-limiting contribution-based Employment and Support Allowance. But evidence is also

emerging of further cuts to disabled people's support from local authorities<sup>40</sup> and closing the Independent Living Fund [1, 15, 16, 19, 20]. We are concerned that disabled people are shouldering a disproportionately large share of the burden despite being disadvantaged from the outset of the proposals.

Although the proposed DLA/PIP changes will not take place until 2013/14, the Government aims have raised an enormous amount of distress and anxiety among disabled people and their families and carers. This is partly due to the nature of announcements and the lack of detail. But in the context of wider public service and benefit reforms, disabled people and their families are becoming increasingly anxious about losing some or all of the support they receive and how (or whether) they will cope as a result. Many disabled people highlighted how DLA assisted in managing conditions and avoiding over-use of the NHS (including GPs and hospitals). Answers in our survey included the following quotes which explain the potential impact in personal terms.

"We would have no transport. It would be impossible to attend prosthetic appointments"

"as a consequence my health would decline...and the long term effect is that I would spent more and more time in hospital"

"I would possibly not attend my hospital appointments as frequently due to the cost to travel to London to do so"

"I need DLA to help prevent my health deteriorating further and to continue to society. DLA is essential to my well being"

"I would be housebound...i would not be able to visit the doctor"

"If DLA was reduced or removed then I would be unable to attend doctors and hospital appointments due to the cost of getting to and from, and my health would be severely put at risk due to not having enough money to either keep myself warm and/or fed"

"We would be in crisis - end of story...My son would start self harming again".

"prescriptions would be out of the question"

"I wouldn't be able to afford the continence products I require each day, as I don't meet NHS requirements"

"worsening of mental and physical health resulting in need for further intervention by social services or possible hospitalization and therefore potentially greater cost to the public purse overall"

"We would be able to afford less or no taxis [for] hospital appointments.... [but] we are both seen by at least 3 hospital clinics and our GP on a regular basis this would be a great disadvantage"

Other people highlighted the impact of cutting DLA on their ability to replace

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<sup>40</sup> With Hammersmith and Fulham expecting £6 million cuts to local services for disabled people and Norfolk Coalition of Disabled People expecting £7 million also.

or maintain equipment/aids:

“I have scoliosis and louredosis of the spine. I cannot stand or walk at all. If [support] is taken away, I will have no means of getting out at all. Social Services are always telling us they have run out of money and cannot help! ... my life wont be worth living if I can't get out or replace my specialist wheelchair when it needs repairs and replacement. It cost forteen thousand pounds. NHS and social services are not going to help me with that”.

“I would be unable to buy aids to daily living and mobility”

“[without DLA] I would not have been able to afford my wheelchair”

“I would not be able to replace equipment, powerchairs, adjustable bed ...Insurance”.

The PIP assessment will take into account whether disabled people use aids/equipment but it is unclear how the cost of maintaining and replacing existing equipment will be met by the new benefit [16].

The perverse effect on the NHS of failing to support disabled people to adequately maintain equipment is apparent. DWP must demonstrate how health costs will be taken into consideration in the development of the new assessment process.

Other disabled people stressed the need to retain DLA to avoid entering residential care or experiencing greater need for local authority social care or housing service support.

This was an issue raised by family carers in particular, with some reporting the following statements.

“Probably could not afford to keep [disabled daughter] living at home, where she has been for the last 42 years”

“If you stop DLA then my wife would end up in a nursing home”

“I would not be able to provide for my wife's needs at home... [she] would probably then need to go into a care home - this would be her worst nightmare and would probably make her SUICIDAL.”

“We would struggle...son would probably go into residential care”.

Individual disabled people also contributed similar statements, including:

“Would have to go into residential care” and  
“i wouldn't be able to live at home with my family”  
“it would become a choice between being in poverty with my family or ending my life so that my family would be better off”  
“Within three months we would be in debt...We would be unable to continue heating our home...It would exacerbate several aspects of our conditions...this inability to look after ourselves would ultimately mean we would either a) have to be moved into care, or institutionalised, or b) result in our deaths”  
“I would have to go into a care home and leave my family...My mental health would definitely suffer and I would probably just give up on living...What point would there be to life”.  
“I rely on my wifes pension to meet & pay our living costs. Without her assistance I would be in poverty like so many single disabled people. Without my DLA I would be in poverty & a financial burden on my wife”.

These potential costs to disabled people, their families, the lost tax/National insurance revenue and costs to the NHS and councils need to be examined as Government plans develop but as yet seem unaccounted for in the rapid timeframe permitted to introduce the Personal Independence Payment [22].

### **Human costs**

Most worrying of the initial sample of responses however, were the disabled people and carers who highlighted the potentially devastating impact of losing DLA. We asked people to describe the impact of losing some or all DLA support and left an open space for people to write their own comments and 9% of the first 900 respondents cited death and suicide as possible outcomes. Some disturbing – but verbatim – statements include:

“I would kill myself to stop being a burden on my family. If I didn't do this I would end up homeless and in an inevitable decline anyway. Might as well get the horror over with”  
“I would not be able to go to work I would not be able to see my family or friends. Therefore I would not want to live”  
“It would add an extra burden on me which I know I couldn't cope with. I would probably have to think about ending it all”  
“my general health would deteriorate even more than it is. I would have nothing to live for. very strong thoughts of suicide would be ever present, or I may just give up & die anyway”

Other respondents highlighted the fear of poverty and exclusion, including comments like:

“I would be thrown into poverty”  
“I would be reduced to poverty. My life is difficult enough now”  
“I am already facing bankruptcy. If I didn’t have my DLA I would literally not have enough money to eat”

We are very concerned that, as the Government progresses with reform, full analysis of who might be affected is provided to ensure disabled people’s concerns are addressed and that fears are alleviated as far as possible [1, 22].

We are also keen for the Government to acknowledge the level of concern and ensure as full an understanding of the potential impact of reform is built into welfare reform legislation. Unfortunately, this does not seem possible given the current timeframe for introducing the PIP.

### **DLA and work**

Of our respondents, 71% said they would rather work than not work. We are very concerned that the current Government proposals may hinder disabled people trying to work [1]. The consultation and Welfare Reform Bill documents suggest that DLA is a barrier to work. This is not necessarily the accurate conclusion to draw from the DWP research<sup>41</sup>.

The evidence suggests that incapacity benefits claimants who also receive the DLA are on average farther removed from the labour market than IB claimants who do not get the DLA<sup>42</sup>. This finding does not necessarily mean that the DLA is a barrier, but it could instead be interpreted to mean that these people are more likely to have greater needs. Furthermore the ‘fear’ that people may lose DLA is linked to the complexity of the overall benefits package and caring responsibilities – not access to or use of DLA per se.

One further reason there may be confusion surrounding DLA and work is DWP staff awareness. 3% of our respondents stated that they had been required to attend a review of their DLA award as they had started work.

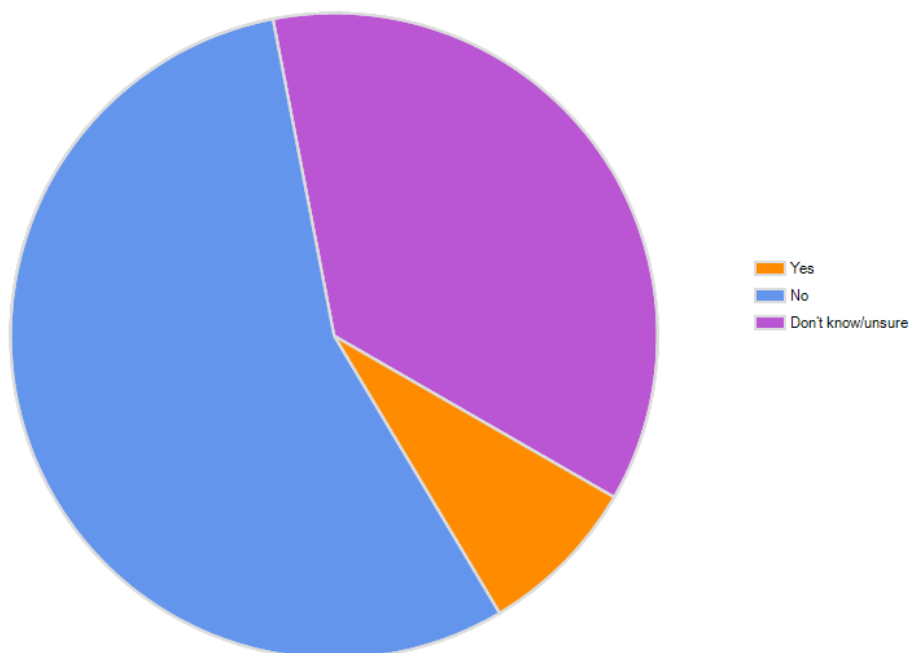
Currently, 27% of our respondents were working either full or part time and 12.5% told us they were receiving working tax credit. Other people told us they use DLA to help them participate in volunteering for example, or that using DLA supported their partner/carer to stay in work. Many told us that DLA helped meet rising fuel costs for work for example – which low salaries might not otherwise meet [2, 3]. Disabled people earn less in average in work than other citizens. Low income is a particular concern for disabled people – and contributing more in work has costs attached (for travel and for work clothes for instance) which disabled people have used DLA to help meet.

<sup>41</sup> *Work and Pensions Longitudinal Study* DWP Information Directorate 2010.

<sup>42</sup> *Disability Living Allowance and work: Exploratory research and evidence review* DWP Research Report, 2010.

But disabled people suggested that losing DLA through the new assessment for PIP would result in having to stop work by a significant margin:

And; if you/the person you care for/represent did not receive DLA would it be possible to continue working?



Only 8% said they would be able to remain in work, with 56% fearing that the knock-on effect of losing DLA would mean having to stop work. This is very worrying.

Some people suggested Access to Work was not flexible enough and that additional work journeys needed paying for and this is where DLA was used for some work-related transport costs.

Disabled people are being required to work through greater sanctions and conditions and an increased experience of Jobseeker's Allowance (rather than Employment and Support Allowance or Incapacity Benefit). DLA has helped some disabled people work and the risk is that not being eligible for PIP will result in an inability to retain employment. This has social and welfare costs attached [22].

Government plans must ensure disabled people are able to retain work – and not rely on employers always being best practice operators with regards to Reasonable Adjustments under equality legislation – or the Access to Work scheme ensuring disabled people and employers always have the appropriate support in place. An assumption of best practice ignores the reality of limited support – and risks undermining broader Government welfare reform plans of ensuring disabled people are able to work [1, 22].



## DLA and access to other support

DLA provides many disabled people with some level of support [18]. It was introduced to help the many disabled people who could not access other sources of support and retains this function in 2011.

But it also acts as a conduit to other sources of support including from councils, other government agencies and beyond.

62% of respondents suggested DLA helped access other support including:

Carer's allowance	23.2%
Council Tax Benefit (CTB)	46.3%
Free-school meals	5.8%
Housing Benefit	35.5%
enhanced disability premium	9.3%
severe disability premium	18.8%
disability premium	16.7%
Free bus pass	48.8%

15% were unsure if DLA helped access other support. But the other interlinked support people mentioned in our survey included:

- Independent Living Fund;
- Additional transport support (including cheaper parking, reduced tunnel tolls, railcards and exemption from vehicle excise duty);
- Eligibility for other schemes (eg Warm Front discounts to secure home insulation);
- Discounts on leisure facilities (including cinema/theatre tickets and at sports grounds for disabled people and/or carers); and
- Fast-tracking to support from councils (eg for adaptations to the home).

We are very keen that in progressing reform the Government provides estimates of how many people will lose access to these forms of 'passport' support systems. It is vital – especially in providing the full equality impact assessment [21] – that the Government is clear how many people stand to lose support, what the support is and whether alternatives are being explored to ensure disabled people and their families are not further disadvantaged.

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## Consultation inaccuracies

The Government plans will have a considerable impact on many disabled people and their families across the country. However, the consultation does not mention the Government's stated objective of cutting 20% of working age DLA expenditure by 2015/16. This is a significant omission [22].

The consultation document also fails to describe who or in what circumstances disabled people might lose support. Disability Alliance has suggested almost 750,000 disabled people will lose support through the new assessment and ending the low rate care DLA rate<sup>43</sup>.

DWP has criticised 'scaremongering' disability organisations but without releasing analysis of how many people may lose support. This inevitably creates a vacuum in which disabled people fear the worst.

The consultation also fails to disclose how families may lose linked support (eg Carer's Allowance) [21, 22]. This hasn't prevented disabled people and their carers contacting Disability Alliance and other representative organisations in great numbers to highlight their fears and concerns over the proposals.

### **Consultation period**

The Department for Work and Pensions (DWP) also chose to consult for just nine weeks in Great Britain. In Northern Ireland the consultation was launched a week later but with the same closure date – leaving just eight weeks to respond. A further week has been added to the consultation due to DWP IT problems.

But the total consultation time is less than the recommendation stipulated in the Government's Code of Practice on consultations<sup>44</sup> [22]. The consultation period included the Christmas and New Year holidays which will have impacted on people's ability to respond – especially disabled people requiring support to respond from organisations closed for public holidays and office closures in December and January.

The impact of the consultation will be most felt by disabled people who will have had very limited opportunities to respond. The communication needs of many of the disabled people potentially affected by the outcome of the consultation may mean the timeframe prevents adequate and effective engagement of a significant number of the people it will directly affect.

### **Review process**

A glaring inaccuracy in the consultation document is the repeated statement that:

'there is no process to check that [DLA] awards remain correct'.

This is misleading. DWP is able to review DLA awards and take into account other evidence to ensure payments are accurate. 14% of our survey respondents had DLA awards reviewed due to assessments for other benefits

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<sup>43</sup> Excluding the 80,000 disabled people set to lose mobility DLA support in care homes.

<sup>44</sup> *Code of Practice on Consultation*, BERR, 2008

being considered. A further 3% of respondents stated that their DLA award had been reviewed as they had started work.

Other respondents told us that their awards were time limited and had been reviewed on schedule. Some respondents did not know why they had been reviewed, simply stating that ‘Jobcentre called me in’ for instance.

Before introducing a new assessment and insisting disabled people, attend face to face interviews it is important that the Government outline the cost of this approach and further detail on whether the existing system could be improved rather than completely overhauled. We believe there are considerable benefits to improving the current review process rather than requiring all disabled people to attend regularly. The Welfare Reform Bill documents highlight that no options were considered for DLA reform except: doing nothing; or reducing the cost by 20%. This impact assessment is very weak and potentially open to legal challenge [21].

People with terminal illnesses will be still be able to receive PIP using a fast-track system according to the consultation. The DWP has also indicated that some disabled people may be exempt from periodic reviews. We would also welcome a better understanding of who may be exempt from the periodic review process [11, 12].

We provide more detail on disabled people’s concerns about the assessment process on page 29.

### **Availability of alternative support**

The consultation also suggests that DLA is:

“part of a wider range of support and services available to disabled people... including in the form of services or direct payments from Local Authorities to meet social care needs”.

In reality, large numbers of disabled people are not eligible for other services – and especially not social services (see page 29). For these people, DLA is an absolute lifeline and was one of the primary aims of introducing the benefit. The Disability Alliance survey on the Government plans to reform DLA has received the following statements from disabled people and their families expressing this sentiment in everyday terms.

“It has contributed to my staying alive.”

“Claiming DLA has given me back a little self-respect and self-worth.”

“DLA lets me live an independent life.. I still can’t afford most things.. but my life is still better with it.. than it would be without it... my mobility car gets me out .. which I would never do if I didn’t have it.. it gives me choice.. please don’t take that away from me.”

“To restrict access to a benefit...will exclude and marginalise disabled people...and incur significant costs when dealing with legal challenges not to mention the costs to the NHS and other public bodies....withdrawing support makes people who are already ill worse and so they cost the NHS more... these proposals will not save the tax payer money though they may save on the DWP's budget and they will cause real physical and emotional harm and....vulnerable people will die because of this especially coming at a time of other welfare reforms and cuts”.

We are very concerned that one impact of reform may be to remove the DLA ‘lifeline’ of support from disabled people unable to access help elsewhere [2, 22].

### **Overall DLA reform timeframe**

We submitted an interim response in January 2011 to ensure our concerns were raised at the earliest opportunity. The Government has published the Welfare Reform Bill before the consultation has closed or DWP have responded to the concerns and ideas raised. It will therefore not be possible for the Government to take consultation responses fully into account in developing the Bill [22].

The timeframe permitted for consultation and the plans for welfare reform risks heightening accusations that the Government has approached DLA reform without due diligence – and with a limited understanding of the potential impact the proposals on disabled people and their families. This considerably undermines Government statements that reforms are fair and that disabled people are protected.

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### **The new assessment process**

Of particular concern to disabled people, carers and advisors responding to our survey is the proposed new assessment [7, 8, 9, 10, 11, 12].

#### **A Work Capability Assessment model?**

The plans for a new assessment, as originally announced, sound very similar to the Work Capability Assessment (WCA). There are many reasons disabled people and public policy practitioners should fear this proposed model for analysing disabled people’s needs.

The welfare reform legislation that introduced the WCA initially had the support of disability organisations. Organisations believed it would be used to help identify disabled people's needs and allocate welfare resources appropriately. This should have ensured disabled people who could work received enough support to get and keep suitable employment – or were able to access the new Employment and Support Allowance support component (where there are no requirements to work for disabled people found unable to undertake any work related activity).

However, the development of the WCA led to disability organisations gradually becoming more critical of the DWP approach which led to the introduction of a WCA which, according to the first independent statutory review published in 2010:

‘is not working as well as it should<sup>45</sup>.’

We agree with this summary and believe a similar model for re-assessing DLA recipients could have significant and avoidable costs. The Welfare Reform Bill suggests the new assessment will cost £675 million to introduce and administer.

### **Identifying needs and costs of living**

Many organisations have concluded that the WCA is unfit for purpose, failing to adequately identify the needs of disabled people<sup>46</sup> [9, 10, 11, 12]. The number of appeals of initial WCA decisions has led to a backlog of over six months in the Tribunals Service across the country<sup>47</sup>. 40% of appeals are successful, which highlights the failures of the WCA. Appeals costs are considerable and at a time of restricting public expenditure the costs of any new assessment (including the potential appeal fees) must be factored into the PIP plans.

The WCA has also been shown to disadvantage certain disabled people, including people with ‘invisible’ disabilities (like mental health problems) and those with fluctuating conditions (eg ME or MS) and needs [7]. The impact of such conditions on day-to-day living can be much harder to effectively determine in a relatively short assessment process. The DWP is examining introducing a points-based model, akin to the WCA, which also risks reintroducing similar challenges experienced by disabled people not accruing enough ‘points’ to secure support to get and find work.

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<sup>45</sup> The Harrington Review, DWP, 2010.

<sup>46</sup> Organisations which have published critical reports on the WCA include Citizens Advice, Macmillan Cancer Support and the National AIDS Trust.

<sup>47</sup> With longer waiting times for hearings in some areas, including over nine months in Northamptonshire.

It is also essential that any new assessment is better able to identify disabled people's needs and provide appropriate support. We believe this must include costs of living [9].

### **Targeting people with the 'greatest need'**

How the new assessment will be focused on disabled people with the 'greatest need' will also be critical. A simplistic approach risks excluding many disabled people who still face additional disability-related costs [7, 9].

The people accessing the lowest rates of DLA are often unlikely to be able to access support elsewhere and cuts to these groups could lead to unsustainable pressure on councils' social care and/or NHS budgets [22]. In the context of council budget cuts and the NHS being under considerable pressure, people's needs could remain unmet elsewhere.

For example, tightening social care eligibility criteria mean that many disabled people who currently claim DLA receive no support from their local social services department – a situation that is worsening<sup>48</sup>. As a result, many people use DLA to access lower level care and support. Consideration must be given to the potential impact of a reduction in DLA on already stretched social care budgets. Many people who are not deemed 'disabled enough' will be hit twice, potentially losing both their DLA and not meeting the threshold for social care.

The 'Way Ahead' focused specifically on people with additional costs, but lower needs who were unable to access alternative support. The original Conservative Government's plan specifically highlighted the problematic availability of alternative support. We believe the PIP proposals risk distorting a principal aim of DLA which was introduced to help disabled people who now appear at risk of losing access to all support.

### **Increase to qualifying period**

The Government proposals suggest that the PIP will only be available to people with a long-term health condition or impairment which has lasted for at least six months [1, 2, 7, 22]. This will exclude a large number of people denying access to people seeking rehabilitation support following accidents, for example, and will prove problematic in relation to some conditions where future need can be difficult to predict.

The consultation document states that:

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<sup>48</sup> In 2007/08, 74% of local authorities set eligibility at 'substantial' or 'critical' only – from *Cutting the cake fairly*, CSCI review of eligibility criteria for social care, Commission for Social Care Inspection, 2008. This figure is expected to rise according to the Care Quality Commission and Coalition on Charging with many councils already consulting on tightening eligibility and increasing costs of care.

‘to ensure that support goes to those with the greatest need, Personal Independence Payment will only be available to those with a long-term health condition or impairment.’

We are concerned about the extension of the ‘qualifying period’ from three to six months and the further expectation that an individual will be required to continue to satisfy the entitlement conditions for at least a further six months.

This undermines one of the aims of DLA, which was intended to:

‘help quickly and effectively’<sup>49</sup>.

For claimants who are not terminally ill, this effectively doubles the qualifying period before a claim can be made. We believe it is inappropriate to make people wait for six months before they can access the support they need [2]. For people with sudden onset conditions, needs and the debilitating effects of treatment are immediate, as are additional costs. There are risks in failing to provide ‘early-intervention’ support including longer term demands for welfare support (through loss of employment or taking longer to adapt).

In addition, the ‘prospective test’ will continue to be particularly problematic for certain groups of claimants – e.g. people with cancer and people with fluctuating conditions where predicting future need can be very difficult.

If the proposals are extended to include children and older people the implications for parents of newborn disabled children are particularly worrying and the Government must clarify if, how and when the new assessment might be extended to disabled children and how people over 65 years of age or retired will have PIP removed as soon as possible.

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## **Automatic entitlements and periodic review**

The consultation document outlines the Government’s intention to move away from a system that awards automatic entitlement [5] for certain conditions, eg Blind people qualifying for high rate mobility payments from April 2011.

Similarly, the Government intends to introduce a new periodic review of all Personal Independence Payment awards [12]. These proposals are based on the understanding that the impact of an impairment or health condition may change over time. We acknowledge that for many disabled people this may be the case. However, for many other disabled people it will not. Someone who has lifelong or long-term condition or disability – for example, someone

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<sup>49</sup> *The Way Ahead: benefits for disabled people* HMSO, 1990, page 23.

with a learning disability or someone who is deafblind – may continue to have the same support needs throughout their life.

The extra costs associated with impairments may also remain unchanged (see page 9-11 for how DLA is currently used and the extra costs cited by disabled people and their families). From this perspective, the existing automatic entitlements to higher rate DLA are an efficient and effective way to allocate some resources – avoiding unnecessary bureaucratic costs.

Recent DWP meetings have suggested some groups of disabled people may receive exemptions [5]. Any system must be fair and transparent and we welcome more detail on the proposed exemptions as soon as possible.

It will not be cost effective for the Government to make people go through an assessment process (and potentially repeated assessments/reviews) where there is clear entitlement to the benefit. This will not only incur significant costs to government but will be highly stressful and potentially counterproductive for disabled people, potentially worsening conditions exacerbated by stress and exertion [9, 11, 12].

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## **Reporting changes in circumstance**

For people with fluctuating conditions, there are real challenges for the review process and, in particular, the increased obligations on the individual to report changes in circumstance [13]. We are very concerned about the proposal to introduce penalties for those who fail to report changes in circumstance.

People with unpredictable and fluctuating conditions such as MS and HIV/AIDS will experience regular and disparate changes in circumstances and requiring reporting of every change may be onerous, stressful and burdensome on both disabled people and DWP staff.

Other disabled people experience very gradual changes in circumstances which mean that the overall change (in an annual period for example) may seem slightly significant but won't have been realised necessarily by the disabled person at any given point. The DWP has previously used this analysis in reporting on 'fraud and error' within DLA<sup>50</sup> – as neither 'fraud' nor 'error' titles are accurate to explain the change in circumstances that mean disabled people may no longer qualify for (the rate of) DLA received. It has not been considered fraud or departmental error for the change by DWP and the new requirements may risk imposing a level of bureaucracy in reporting changes that is unnecessary and costly.

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<sup>50</sup> *Fraud, Error and other Incorrectness in Disability Living Allowance* DWP, 2005.



We believe the PIP assessment must remain focused on the costs of the overall condition/impairment rather than simple changes in the condition itself [22]. To enable some disabled people to manage health conditions requires frequent, small payments which are not met by the NHS or other sources. To remove DLA may risk rising avoidable healthcare costs unless the PIP assessment takes account of costs associated with managing conditions, including the extra costs incurred for maintaining aids and equipment.

Rather than introducing penalties, the Government should issue clear guidance about what represents changes in circumstance that claimants would be required to report and make it as easy as possible for them to do so. There should also be clear information about what reporting a change in circumstance could mean for the claimant.

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## **Residential care homes and mobility**

We are opposed to the removal of the mobility component of DLA for people living in residential care [22]. This is a regressive step which will deny 80,000 disabled people<sup>51</sup> independence and the opportunity to participate in community life. This measure would also affect families of disabled children who may lose the ability to transport children from residential schools at weekends and in non-term times. This issue is being examined by human rights experts for compliance with UK, EU and UN legislation.

The Government has committed (in the DLA consultation) to promoting social justice for disabled people and has emphasised increasing independence, participation and opportunities for employment. However, we are gravely concerned that the removal of the mobility component of DLA for those living in residential care will considerably undermine these aims and risk greatly reducing the independence and autonomy of disabled people – and potentially their families.

The mobility component of DLA helps people to pay for things like accessible transport, or mobility aids such as an electric wheelchair. It makes a vital difference in ensuring that people can leave their home independently and participate in everyday activities that non-disabled people take for granted, such as meeting friends, attending a leisure centre or getting to college. In some care homes there are schemes where people's DLA mobility allowance is pooled and used to buy or lease a car which care staff can then use to take disabled residents out into the broader community at will.

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<sup>51</sup> <http://www.publications.parliament.uk/pa/ld201011/ldhansrd/text/101209w0001.htm#10120942000766>  
9 December 2010

The assumption behind the proposal to remove the mobility component of DLA from those living in residential care is wrong. It is based on the misunderstanding that people living in residential care situations have all of their needs provided for by the package of support purchased by councils and is therefore a case of double funding. This is incorrect. The reality is that an individual's package of support does not provide for all aspects of an individual's life – it only funds basic care. The vast majority of a disabled person's mobility needs – and the costs associated with them – are un-assessed by local authorities as they are not a direct requirement of care law.

The Prime Minister and other Ministers have also suggested DLA is not required for disabled people in care homes using a rationale which likens care home residents to hospital inpatients. This is also inaccurate and offensive to many disabled people who choose to live in care homes to access personal support. Some people living in care homes work; others volunteer. Many use DLA mobility payments to help link into local communities and participate in other ways. This is not the case for hospital inpatients undergoing medical treatment/operations; but these activities will be lost through removing DLA entitlements.

It also risks preventing care home residents attending medical appointments (eg to help manage health conditions) – which poses further potential threats to the NHS budget if the proposals are implemented.

We believe the Government must reconsider the impact of this proposal to understand the harmful outcome and should target reducing the national deficit elsewhere – Disability Alliance supports a financial transactions tax for example, with revenue raised hypothecated to tackle UK poverty.

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## **Summary of recommendations**

1. That Government Departments (including HMT, DH, DCLG and DWP) work in partnership with disability organisations to identify and mitigate the potential costs and fuller impact of reducing DLA support, including for equality impact assessment purposes.
2. That DWP co-produces further communications on reform with representative disability organisations to prevent misunderstandings and ensure reform is better understood and anxiety is minimised.
3. That eligibility for passported support, such as Carers Allowance, be linked to the lowest payments of the PIP to ensure the impact on disabled people and their families is as minimised as possible.
4. That the Government consider a sliding scale of support and not a regimented two payments system (lower and higher). That one-off costs be part of a sliding scale approach.

5. That disabled people's higher costs be further analysed to ensure PIP levels of payments will be able to help support disabled people well.
6. That the Government consider disabled people's support for the need to link some impairment types to rates of PIP payments.
7. That any new assessment is in-keeping with the personalisation and right to control agenda. The new assessment should be as self-directed as possible (using independent medical evidence) and avoid being predominantly medical in approach.
8. That the new assessment process be streamlined and avoid unnecessary bureaucracy.
9. That any new assessment be analysed for potential over-bureaucratisation and avoidable new costs, with a stronger focus on minimising service costs and maximising restricted resources for disabled people.
10. That expert medical advice be sought rather than rely on a new assessment process to identify all a disabled person's needs and costs in what is likely to be a very short timeframe.
11. That DWP work in partnership with Disability Alliance and the Disability Benefits Consortium to undertake sample PIP assessments with disabled people to ensure problems are identified and addressed before the assessment is finalised or implemented. Sample tests can include the disabled people who contributed to the survey we have undertaken and who volunteered to remain involved; we have a cross section of impairment types, ages and current DLA rates.
12. That the PIP assessment include maintenance and ongoing costs of aids, equipment and other essentials to achieving daily living.
13. That the PIP assessment should only take account of certain aids and adaptations (preferably those identified in previous DLA case law) and only where these are available, maintainable or can reasonably be obtained without undue delay, cost or obligations on a disabled person.
14. That the new assessment include scope to assess ongoing essential impairment-related costs of living for disabled people.
15. That Government proposals be analysed fully to ensure disabled people do not lose all access to support as a result of the PIP assessment (i.e. not just to PIP but to other support/services).
16. That the new assessment must be piloted to ensure any challenges are identified early and mitigated before national rollout.
17. That rollout of the new assessment is closely monitored to ensure no adverse and/or unintended affects on disabled people, their families or other government's resources (eg councils, Tribunals or the NHS).
18. That DLA case law (Secretary of State v Fairey (R(A)2/98) is upheld and the PIP remains a benefit designed to allow disabled people to participate in society.
19. That current DLA recipients' maintenance of 'active and independent lives' be monitored as part of PIP reviews.

20. That the PIP implementation be reviewed independently and annually from 2014 onwards.
21. That statistics launched alongside the Welfare Reform Bill relating to DLA meet the agreed terms on clarity of the JCP stakeholders and customers' advisors forum.
22. That DWP and HMT work with disability organisations on ensuring the PIP does not disincentivise work.
23. That the Government seek to work in partnership with disability organisations on developing guidance regarding what represents 'change' requiring reporting to DWP, rather than introduce a penalty system based on an inadequate set of criteria.
24. That a cross-department group of Ministers including from DWP, HMT, DH and DCLG examine the care homes and mobility DLA plans in more detail in partnership with care home operators, social service representatives, local government representatives as well as disability organisations. This group should agree a process for ensuring disabled people do not lose support and no changes should be implemented without agreement and/or that result in disabled people losing access to personal, controlled arrangements for their mobility needs.
25. That extended periodic reviews should be permissible in cases where needs remain stable and are unlikely to change. DWP should work with disability organisations to identify examples.
26. That the principles of *Moyna v Secretary of State for Work and Pensions* be applied when considering assessment, especially in relation to variable and fluctuating conditions.

### **Further requests**

- That the Government urgently provide estimates and modelling of who might lose access to PIP who is currently receiving DLA.
- That the Government urgently provide estimates and modelling of who might lose access to PIP who is currently eligible to receive DLA.
- That the Government urgently provide estimates and modelling of who might lose access to PIP who is currently supporting/caring for someone receiving or eligible for DLA.
- That a full disability poverty audit is undertaken on the proposals.
- That the Government clarify whether it is the plan for people retiring or reaching 65 years of age to automatically lose PIP.
- That the Government urgently clarify what the PIP rates will be.
- That DWP respond in full to the DLA reform consultation responses.

## **Appendix A: DLA survey respondents**

The survey on DLA reform, drafted by Disability Alliance with support from a range of partner organisations, ran online from 6<sup>th</sup> December 2010 to 14<sup>th</sup> February 2011.

Almost 1,750 people (1,739) completed our survey, though postal responses were also received from some respondents for accessibility and IT reasons.

Not everyone answered all the questions.

We will be providing a fuller report on the findings and respondents of the survey in due course, including by age of recipient.

We asked about receipt of DLA and:

- 61% of respondents received DLA;
- 21% cared for someone receiving DLA;
- 13% advised DLA recipients; and
- 5% knew someone who needed DLA.

82% of the DLA recipients were disabled people according to our survey respondents.

Of those who answered the gender question 65% were women and 35% men.

87% of the DLA recipients were receiving DLA care payments:

- 41% at the higher rate;
- 34% at the middle rate;
- 19% at the lower rate; and
- 6% were unsure of the rate.

86% were also receiving DLA mobility payments:

- 69% at the higher rate;
- 24% at the lower rate; and
- 7% were unsure of the rate.

## Appendix B: The Government DLA reform consultation questions

1. What are the problems or barriers that prevent disabled people participating in society and leading independent, full and active lives?
2. Is there anything else about Disability Living Allowance (DLA) that should stay the same?
3. What are the main extra costs that disabled people face?
4. The new benefit will have two rates for each component:
  - Will having two rates per component make the benefit easier to understand and administer, while ensuring appropriate levels of support?
  - What, if any, disadvantages or problems could having two rates per component cause?
5. Should some health conditions or impairments mean an automatic entitlement to the benefit, or should all claims be based on the needs and circumstances of the individual applying?
6. How do we prioritise support to those people least able to live full and active lives? Which activities are most essential for everyday life?
7. How can we best ensure that the new assessment appropriately takes account of variable and fluctuating conditions?
8. Should the assessment of a disabled person's ability take into account any aids and adaptations they use?
  - What aids and adaptations should be included?
  - Should the assessment only take into account aids and adaptations where the person already has them or should we consider those that the person might be eligible for and can easily obtain?
9. How could we improve the process of applying for the benefit for individuals and make it a more positive experience? For example:
  - How could we make the claim form easier to fill in?
  - How can we improve information about the new benefit so that people are clear about what it is for and who is likely to qualify?
10. What supporting evidence will help provide a clear assessment of ability and who is best placed to provide this?
11. An important part of the new process is likely to be a face-to-face discussion with a healthcare professional.
  - What benefits or difficulties might this bring?
  - Are there any circumstances in which it may be inappropriate to require a face-to-face meeting with a healthcare professional – either in an individual's own home or another location?
12. How should the reviews be carried out? For example:
  - What evidence and/or criteria should be used to set the frequency of reviews?
  - Should there be different types of review depending on the needs of the individual and their impairment/condition?

13. The system for Personal Independence Payment will be easier for individuals to understand, so we expect people to be able to identify and report changes in their needs. However, we know that some people do not currently keep the Department informed. How can we encourage people to report changes in circumstances?
14. What types of advice and information are people applying for Personal Independence Payment likely to need and would it be helpful to provide this as part of the benefit claiming process?
15. Could some form of requirement to access advice and support, where appropriate, help encourage the minority of claimants who might otherwise not take action? If so, what would be the key features of such a system, and what would need to be avoided?
16. How do disabled people currently fund their aids and adaptations? Should there be an option to use Personal Independence Payment to meet a one-off cost?
17. What are the key differences that we should take into account when assessing children?
18. How important or useful has DLA been at getting disabled people access to other services or entitlements? Are there things we can do to improve these passporting arrangements?
19. What would be the implications for disabled people and service providers if it was not possible for Personal Independence Payment to be used as a passport to other benefits and services?
20. What different assessments for disability benefits or services could be combined and what information about the disabled person could be shared to minimise bureaucracy and duplication?
21. What impact could our proposals have on the different equality groups (our initial assessment of which is on page 28) and what else should be considered in developing the policy?
22. Is there anything else you would like to tell us about the proposals in this public consultation?

## **Appendix C: The answers from DWP to DA questions**

### **How was the decision to cut 20% of working age DLA expenditure reached?**

The 20% reduction in forecast working-age expenditure was announced in the June 2010 Budget. Expenditure on the benefit has risen dramatically over the last decade and the Coalition Government decided that a reduction was necessary to bring the benefit back onto a sustainable footing.

As a result of these reforms and focussing resources on those who need them most, we will continue to provide essential support whilst delivering a 20% reduction in the forecast DLA expenditure for working-age customers. Reducing working age projected expenditure by 20% in 2015/16 means bringing working age expenditure back to 2009/10 levels in real terms.

### **How many people does DWP estimate will lose all DLA (and not receive any PIP) support as a result of the reform?**

### **How many people does DWP estimate will lose some DLA support as a result of reform?**

### **How many people will lose Carer's Allowance as a result of reform?**

### **How many people are likely to lose other inter-linked support?**

At this time we are in the process of designing the new objective assessment and cannot comment further on what the process or the assessment would look like or entail. Therefore, it is not possible to assess the impact of the reform of DLA on existing or future benefit recipients. We want to have a full and open discussion ensuring we get these reforms right, which is why we are seeking views on our proposals for reform as part of our public consultation.

### **How much does the Government envisage spending on implementing the new assessment process? And how much will it cost to periodically review DLA claimants?**

It is proposed that Disability Living Allowance will be replaced by Personal Independence Payment from April 2013, with an objective assessment as an integral part of that benefit. The cost of implementing the Personal Independence Payment is dependent on the design of the new objective assessment and how it is delivered. The current consultation exercise will help inform these decisions. The Government will set out further detail at the earliest opportunity.

### **Will the Government be extending the new assessment and PIP to disabled children and people over 65 years of age and if so when?**



In the first instance we will reassess the working age (16-64) caseload. We will consider carefully how the reforms will impact on children and those aged over 65. However, no decisions have been made and we are seeking views on this proposal as part of our public consultation.

**When will the Government be providing further detail on conditions/impairment groups which may receive an automatic transfer from DLA to PIP (if any)?**

No decisions have been made and we are seeking views on this proposal as part of our public consultation.

**When will the Government provide more detail on the timeframe for the proposed 'periodic reviews' and will some conditions/impairment groups also receive exemptions from this process?**

No decisions have been made and we are seeking views on these proposals as part of our public consultation.

Reviewing awards is about making sure people continue to receive the correct amount of benefit; this means that some individuals may see a reduction in their award, but others may see increases. How frequently we will review an award and how we carry out the review will vary depending on the individual's needs, the likelihood of their health condition or impairment changing and potentially the successful use of aids and adaptations and we are asking people for their views on this.

**How will costs of living be factored into the PIP assessment process?**

We know that disabled people face additional costs to leading full and active lives. The Personal Independence Payment will continue to provide a contribution towards these costs. Although PIP, like DLA, will exist to contribute to the costs associated with disability, it is not possible for us to assess the actual costs incurred by disabled people. This would be extremely time consuming to administer and would require inconsistent and subjective decision making. To help us in targeting benefits to those who need them most we therefore use a proxy measure. In this case we are planning to assess an individual's ability to carry out everyday activities and participate in society.