



House of Commons  
Work and Pensions Committee

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# Government support towards the additional living costs of working-age disabled people

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Seventh Report of Session 2010–12

## *Volume I*

*Volume I: Report, together with formal minutes, oral and written evidence*

*Additional written evidence is contained in Volume II, available on the Committee website at [www.parliament.uk/workpencom](http://www.parliament.uk/workpencom)*

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## The Work and Pensions Committee

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### Committee staff

The current staff of the Committee are Carol Oxborough (Clerk), Andrew Hudson (Second Clerk), James Abbott (Committee Media Adviser), James Clarke (Inquiry Manager), Emma Sawyer (Senior Committee Assistant), Hannah Beattie (Committee Assistant).

### Contacts

All correspondence should be addressed to the Clerk of the Work and Pensions Committee, House of Commons, 7 Millbank, London SW1P 3JA. The telephone number for general enquiries is 020 7219 2839; the Committee's email address is [workpencom@parliament.uk](mailto:workpencom@parliament.uk)

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## Summary

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Disability Living Allowance (DLA) is unique in the benefit system in that it provides non-means tested support for anyone who incurs additional living costs as a result of their long-term disability or health condition. The Government's plans to introduce a new benefit to replace DLA for working age claimants, the Personal Independence Payment (PIP), were based on HM Treasury's assumption, which drew on evidence from the Work Capability Assessment (WCA) for Employment and Support Allowance (ESA), that a new eligibility assessment would produce a saving of around 20% on the projected expenditure on the DLA budget for working-age claimants in 2015–16. This implies that some current DLA recipients will lose financial support and that the bar for new claimants will be set higher.

The necessity of identifying potential savings across Government in the current fiscal climate is acknowledged. However, HM Treasury's assumption that a 20% reduction in expenditure on this benefit could be achieved by 2015–16 is uncertain. Projections made by analogy to the process for reassessing incapacity benefit claimants under the WCA may be inaccurate. Demographic changes are a significant factor in the increase in DLA expenditure, particularly the growth in the number of people over state pension age who retain DLA. This will not be affected by the introduction of PIP which is intended only to apply to working-age DLA claimants.

There are a number of arguments for reforming DLA. It has become an increasingly complex benefit, evidenced by the large and growing amount of case law. The purpose of DLA is not always well understood by claimants and their advisers, the general public or the media. For example, it is frequently misunderstood to be an out-of-work benefit. Claiming DLA can be difficult and it is not always clear who will be eligible. There is not a consistent and clear system for reviewing DLA awards—evidence suggests that around 11% of DLA awards are overpaid due to unreported gradual changes in circumstances. However, it should also be borne in mind that a significant number of people who might be eligible for DLA do not currently claim it.

The Chancellor of the Exchequer's announcement of the intention to reform DLA made the Government's communications task a difficult one. It is unfortunate that a background of budget cuts has created unnecessarily high levels of anxiety about this reform amongst DLA recipients. Since then, DWP has taken steps to involve disabled people in the process for devising and implementing PIP and this has proved to be effective to some extent.

Much of the media coverage of DLA reform has been negative and has often conflated DLA with out-of-work benefits such as ESA. This helps to fuel negative perceptions of disabled people. While the Government cannot control the editorial line taken in the media, it should exercise extreme care in the way it engages with the media on disability benefits and take further steps to explain the reasons for the reform to the media and the public. In particular, a more responsible approach to explaining and providing context is required when the Government releases statistics about disability benefit claimants.

The Government's confirmation that it does not intend to adopt a "big bang" approach to implementation is welcome. It has announced its intention to limit new claims to a few thousand per month for the first few months and to confine implementation initially to

one geographical area. The period prior to national roll-out should be used to learn the early lessons which emerge from this small-scale implementation and to make changes quickly where necessary.

As has been shown in the move from Incapacity Benefit to Employment and Support Allowance, reassessment of existing claimants is even more complex than assessing new claims. Reassessment of existing DLA claimants should only proceed once DWP is confident that the assessment process is accurate and working properly for new claims.

More reassessment of claims is necessary than has been the case with DLA. However, too frequent reassessment risks wasting public money and causing stress and anxiety to disabled people. The personal interview should play an important part in assessing many PIP claims but evidence from medical professionals expert in a particular condition and with a detailed and longstanding knowledge of the claimant should be given due weight in the assessment process. Once the initial assessments for PIP have been completed in the first geographical area, the Government should look again at the value of face-to-face assessments for PIP claims where claimants' conditions are severe and unlikely to change. These steps may help to avoid cases going to appeal, with the accompanying costs and delays.

Until very recently the information released by the Government included no estimate of the number of people likely to be affected by the reform. It is still not possible to ascertain, from the latest information released in January, from which DLA rate combinations the projected PIP caseload reduction of 500,000 claimants by 2015–16 (compared to projections for DLA) will come and therefore which current DLA recipients are likely to have their benefit withdrawn altogether. DWP should set out further case studies to show which claimants who currently qualify for working-age DLA will not be eligible for PIP and which will be eligible but at a lower rate. In future, major benefit reform proposals should be accompanied by detailed and comprehensive analysis of the likely impacts of reform as soon as practicable.

The PIP assessment criteria, as drafted, tend towards the “medical model” of disability. Significant improvements have been made in the second draft but the criteria will still assess people's impairments rather than the barriers to full participation in society which they face. As part of the formal consultation with disability representative organisations on the second draft of the criteria now under way, the Government should consider how activity descriptors could take account of the impact of such factors as housing and access to public transport. A further trial of the assessment criteria should be undertaken following the formal consultation now under way, and before they are laid down in Regulations.

After a difficult beginning, DWP deserves credit for the effort it has made to date to include disabled people and their organisations in the design process for PIP and for listening to some of their concerns. It dropped the proposals to end payment of the DLA mobility component for care home residents after the Low Review and to extend the three-month qualifying period under DLA to six months under PIP. It is important that the views of disabled people are fully recognised in the Government's further formal consultation on the revised criteria.

DWP must avoid repeating the well-documented and serious flaws in the original WCA system. The PIP assessment process needs to be empathetic, and avoid the mechanistic, tick-box approach adopted in the WCA in 2008. Private companies administering the assessment should be contractually obliged to adopt this more empathetic approach and to allocate sufficient time to allow for this in each assessment.

DWP appears to have learned lessons from the problems arising from the monopoly supplier arrangement for the WCA. The contracting arrangements for the PIP assessment seem likely to include a framework system which will allow for competition. A further lesson should be learned in terms of linking payment of public funds to private companies directly to performance. The PIP assessment contracts should stipulate that companies will only be paid for assessment reports that are “right first time” in the majority of cases. Tighter monitoring and regulation of private companies undertaking benefits assessment on behalf of DWP is required.

# 1 Introduction

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## Background

1. The introduction of Disability Living Allowance (DLA) in 1992 was a policy response to well-established evidence that disabled people and their families suffer greater disadvantage and are more likely to suffer poverty than non-disabled people.<sup>1</sup> It was designed to contribute towards the extra costs incurred by disabled people in overcoming barriers to participation in society. DLA replaced two existing benefits—Mobility Allowance (MobA) and Attendance Allowance (AA)—for working-age claimants.<sup>2</sup>

2. DLA has a mobility component and a care component. Mobility and care were chosen on the basis of research by the Office of Population Censuses and Surveys, as the most appropriate proxies to establish entitlement to the benefit. Measuring each individual's *actual* extra costs was thought to be too administratively complex and prohibitively expensive.<sup>3</sup> The mobility component is paid at two different rates. The care component is paid at three rates. Claimants are paid one or both components, at the appropriate rate, depending on their needs. This structure means there are 11 different “rate combinations”. The weekly amounts currently payable to recipients are set out below:

<b>Care component</b>	lower rate	£19.55
	middle rate	£49.30
	higher rate	£73.60
<b>Mobility component</b>	lower rate	£19.55
	higher rate	£51.40

3. There has been a considerable rise in the total number of people, of all ages, receiving DLA and the cost of the benefit to the Exchequer. There were 3.2 million people in receipt of DLA as at February 2011 compared to 1.1 million people in 1992–93. Total DLA expenditure rose from £3.2 billion in 1992–93 to £12.3 billion in 2009–10 in real terms (2011–12 prices).<sup>4</sup>

## The Government's proposals

4. In the June 2010 emergency Budget, the Chancellor of the Exchequer announced that DLA would be reformed by the introduction of a new assessment for eligibility. He said that the rationale for reform was that “three times as many people claim it today than when it was introduced 18 years ago, and the costs have quadrupled in real terms to more than

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1 See, for example, Department for Social Security, *The Way Ahead: Benefits for Disabled People*, Cm 917, January 1990.

2 *Welfare Reform Bill: reform of disability benefits, Housing Benefit, and other measures*, Research Paper 11/23, House of Commons Library, March 2011.

3 Department for Work and Pensions, *Disability Living Allowance Reform*, Cm 7984, December 2010, para 10.

4 Ev 96



£11 billion a year”.<sup>5</sup> In the policy costings document accompanying the June 2010 Budget, HM Treasury’s assumption was that a new eligibility assessment would result in a 20% reduction in caseload and expenditure.<sup>6</sup> The Chancellor said that the effect of reducing expenditure would be to enable the benefit to be focused on “those with the greatest needs”. He also said the new assessment process would be “simpler than the complex forms” used to apply for DLA.<sup>7</sup> The reforms announced in the Budget were planned to be brought in over three years, beginning in 2013–14, with 25% of the existing caseload reassessed in year one, a further 50% by the end of year two and the remaining 25% by the end of the process in 2015–16.

5. The DWP’s December 2010 Green Paper, *Disability Living Allowance reform*, set out proposals to replace DLA, for *working-age* claimants, with a new benefit—the Personal Independence Payment (PIP). Before the consultation period ended, the legislative framework for introducing PIP was included in the current Welfare Reform Bill, which is reaching the end of its parliamentary stages.

6. The Government has said that the proposed new benefit will have the same purpose as DLA i.e. to “contribute to the extra costs of overcoming the barriers faced by disabled people to lead full and active lives”.<sup>8</sup> PIP will share several other similarities with DLA: it will not be means-tested or taxable; payment will not depend on claimants having made National Insurance contributions; it will be payable regardless of employment status; and special rules will be maintained for people who are terminally ill.

7. The Government does, though, propose some major changes. It intends to focus support on those with the greatest needs and/or barriers to participation and thereby reduce caseload and expenditure. This would be achieved by revising the eligibility criteria and introducing a new, “more objective” assessment for eligibility, which for most people will mean a face-to-face assessment with a healthcare professional. It also aims to make the eligibility rules clearer and to simplify the new benefit by having fewer “rate combinations”. Other key changes proposed include ending automatic entitlement for certain conditions and impairments and regular review of all awards. The Government also originally planned to extend the qualifying period from three to six months but this proposal was withdrawn at Report stage in the Lords on 17 January.<sup>9</sup>

## Our inquiry

8. The proposal to replace working-age DLA with a new benefit is controversial. Many disabled people and their representative organisations have been vociferous in their opposition to elements of the Government’s plans, particularly the proposal to reduce expenditure by focusing on “those with the greatest needs”.<sup>10</sup> **As we have taken the**

5 HC Deb 22 June 2010, col 173.

6 HM Treasury/HM Revenue & Customs, *Budget 2010 Policy Costings*, June 2010, p 36.

7 HC Deb, 22 June 2010, col 173.

8 Department for Work and Pensions, *Disability Living Allowance reform*, December 2010, Cm 7984, p 11.

9 HL Deb, 17 January 2012, col 550.

10 See, for example, “New disability test ‘will cut off lifelines’”, *The Times*, 9 July 2011, “We’re not being listened to”, *The Guardian*, 13 July 2011 and Disability Rights Partnership, *End of a Lifeline? Ending Disability Living Allowance to introduce Personal Independence Payment*, DLA reform consultation response, February 2011.

**relatively unusual step of conducting our inquiry while parliamentary scrutiny of the relevant Bill was under way, we trust that the Government will take our conclusions and recommendations into account in its formal consultation on the revised assessment criteria announced in January and then in drafting the relevant Regulations, which will set out the detailed structure and rules for PIP.**

9. We received 59 written submissions and held three oral evidence sessions: with academics and benefits experts; disability representative organisations; and Maria Miller MP, the DWP Minister for Disabled People and DWP officials. A full list of witnesses is set out at the end of this report.

10. We held an informal meeting in Parliament with disabled people and their representatives to hear their views on reform before the inquiry was launched. We also visited Aberavon in Neath Port Talbot, south Wales to hear the concerns of people who are likely to be directly affected. We would like to thank everyone who contributed to the inquiry, particularly those who took the time to attend our public meeting, which we found enormously helpful.

### **Structure of this report**

11. Chapter 2 looks at the existing objectives for DLA and the changes the Government hopes to bring about through the introduction of PIP. In Chapter 3 we assess the Government's consultation and communications process for the reform. Chapter 4 examines the Government's performance to date in assessing the likely impacts of the policy change. In Chapter 5 we analyse the eligibility criteria and the new assessment for PIP. Chapter 6 assesses the proposals for implementation and contracting arrangements.

12. PIP is currently only intended to apply to working-age DLA claimants and the Government has not yet made clear its plans for any future changes relating to claimants under 16 years-old and those over the state pension age. This Report therefore focuses on the working-age cohort of claimants. We may return to look at DLA reform should the Government put forward further proposals affecting these other groups of claimants.

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## 2 Policy objectives

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13. The Government recognises that DLA helps disabled people to meet the extra costs they incur in participating in society. As we have noted, PIP will retain some of the valued features of DLA. In particular it will remain a non-means-tested, tax-free cash payment, paid regardless of employment status, which can be used as recipients choose towards extra costs incurred. However, the Government argues that DLA has key weaknesses and is “no longer in step” with disabled people’s needs. Its intention is that the introduction of PIP should address: the complexity of DLA and the misunderstanding of its purpose; the lack of a sufficiently rigorous system of award reviews; and “unsustainable” rises in caseload and expenditure.<sup>11</sup> DWP also states that “A significant proportion of DLA recipients believe that DLA is an out-of-work benefit.”<sup>12</sup> This chapter considers the objectives and current administration of DLA and examines the rationale for the Government’s policy objectives for PIP.

### DLA policy objectives

14. DLA was introduced because the combination of the two existing benefits—Attendance Allowance (AA) and Mobility Allowance (MobA)—was not considered to be meeting the extra costs incurred by some groups of working-age disabled people, particularly those with learning disabilities and the visually impaired. The 1990 White Paper, *The Way Ahead: Benefits for Disabled People*, had drawn on evidence from a wide-ranging survey of the circumstances of disabled people commissioned from the Office of Population Censuses and Surveys. This had found there were some people with moderate to severe disabilities who failed to qualify for either AA or MobA. The White Paper concluded that these people needed more support.<sup>13</sup>

15. Another major objective of DLA was to introduce self-assessment, to enable disabled people to describe the impacts of their disabilities rather than be subject to routine medical assessments (as had been the case with AA and MobA). These assessments had been criticised as inappropriate and “providing little more than a snapshot” of people’s health conditions. Self-assessment was intended to be administratively simple and allow individuals to provide a fuller account of their personal circumstances.<sup>14</sup>

### How DLA works

16. To qualify for the mobility component, claimants must have one or more of the following: walking difficulties caused by their disabilities; severe discomfort or risk of endangering health or life by making the effort to walk; no legs or feet; both 100% disabled because of loss of eyesight *and* not less than 80% disabled because of deafness; severely mentally impaired with severe behavioural problems; need guidance or supervision most of the time when outside in unfamiliar places; or certified as severely sight impaired.

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11 Department for Work and Pensions, *Disability Living Allowance Reform*, Cm 7984, December 2010.

12 *Ibid*, para 17.

13 Department for Social Security, *The Way Ahead: Benefits for Disabled People*, Cm 917, January 1990.

14 Social Security Committee, Fourth Report of Session 1997-98, *Disability Living Allowance*, HC 641, para 7.

Claimants receive lower rate mobility component if they satisfy the criterion: “need guidance or supervision most of the time when outside in unfamiliar places”. They are eligible for higher rate mobility component if they have one or more of the other, more severe, walking difficulties.

17. To qualify for the care component, claimants must have a disability severe enough for them to either: need help with things such as washing, dressing, eating, getting to and using the toilet, or communicating needs; need supervision to avoid putting themselves or others in substantial danger; need someone with them when on dialysis; or be unable to prepare a cooked main meal for themselves. Claimants qualify for the lowest rate if they need help for some of the day or are unable to prepare a cooked main meal. The middle rate is awarded to those who need help with personal care frequently or supervision continually throughout the day only, help with personal care or someone to watch over them during the night only, or someone with them while on dialysis. The highest rate is paid to those who need supervision frequently throughout the day and night.<sup>15</sup>

18. Claims for DLA are made by completing a 55-page application form. The form is accompanied by 16 pages of explanatory notes. The form asks 62 questions, including about: the claimant’s illnesses and disabilities and the treatments or help they receive (10 questions); how well the claimant can get around outdoors (11 questions); care needs during the day (14 questions); care needs during the night (4 questions); time spent in hospitals and care homes (3 questions); and other benefits received (1 question). The form can be downloaded and printed from the Directgov website. Claimants also give details of their GP and any other doctor, nurse, therapist or social worker they have seen in the last 12 months. Claimants are encouraged to submit with their application form any assessment reports or care plans from professionals who have treated them.

19. Claims are then considered by Decision Makers (DMs) in the Pensions, Disability and Carers Service (PDCS) within DWP. DMs are guided by an “A-Z of medical conditions”, which “contains background information on the more common medical conditions in DLA/AA claims, their treatment, the likely disabling effects together with the likely impact on ability to self care and get around”.<sup>16</sup> If a claimant’s description of the effects of their illness or disability does not match that outlined in the guidance, or if the guidance on the particular illness or disability advises the DM to seek further medical evidence, the DM will ask the claimant’s GP to complete a “factual report”.

### ***The role of face-to-face assessments in the current claim process***

20. If the DM decides, after receipt of the factual report, that they still have insufficient information on which to base a decision, they can require the claimant to attend a medical examination carried out by Atos Healthcare.<sup>17</sup> The examination involves an interview and, if considered appropriate, a physical examination by an Atos Healthcare professional

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15 Information from Directgov: [www.direct.gov.uk](http://www.direct.gov.uk)

16 Available on the DWP website: <http://www.dwp.gov.uk/publications/specialist-guides/medical-conditions/a-z-of-medical-conditions>. This online guidance is gradually replacing the DSS/DWP publication, *The Disability Handbook: A Handbook on the Care Needs and Mobility Requirements likely to arise from various Disabilities and Chronic Illnesses*—a 275 page guide last updated in November 1991, ahead of the introduction of DLA in 1992.

17 *Disability Living Allowance reform*, SN/SP/5869, House of Commons Library, February 2011.

(HCP). The HCP writes up a report of the examination and returns it to the DM. The DM then makes a decision about the claim on the basis of the combined evidence from the application form, any additional information provided, such as a GP's factual report, and the report of the Atos assessment.

21. DWP recently released statistics on the use of evidence in decisions made on new DLA claims in 2010. The statistics indicate which piece of evidence DMs considered to be the main basis of their award decision:

- 6% were based on a face-to-face assessment;
- 16% were based on the claim form;
- 42% on a GP's report; and
- 36% on "other" paper-based sources of evidence.

"Other" evidence can include "phone calls to the claimant or their carer, the claimant's Personal Care Support Plan, information from a Social Worker, or from an Occupational Therapist, physiotherapist or other Allied Health Professional, information obtained as part of the claimant's application for Incapacity Benefit or Employment and Support Allowance, or information obtained from a Hospital report".<sup>18</sup>

### ***The Required Period Condition and length of DLA awards***

22. DLA is not payable until the claimant has met the eligibility criteria for at least three months (the "qualifying period") and is expected to continue to meet the criteria for at least a further six months (the "prospective test"). These periods together make up a Required Period Condition of nine months and were introduced to focus DLA on "those people whose disabilities will have a considerable and continual impact on their lives".<sup>19</sup>

23. DLA can be awarded for life or for a fixed period. Claimants with fixed awards have to make a renewal claim shortly before the expiry of their existing award. Renewal claims are treated in exactly the same way as new claims.

## **PIP policy objectives**

### ***Addressing misunderstandings and complexity of DLA***

24. DWP's view is that DLA is not well understood: people are unclear about the purpose of the benefit and the entitlement criteria are insufficiently clear to ensure that people know whether or not they are likely to qualify. Qualitative research published by DWP in 2010 found a wide range of perceptions amongst recipients about the purpose of DLA. This depended to some extent on the advice they were given by DWP staff and external welfare rights advisers. Commonly held misperceptions included that DLA was

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18 Department for Work and Pensions, *DLA Award Values and Evidence Use for New Claims in 2010, in Great Britain*, November 2011, p 5.

19 *Disability Living Allowance reform, SN/SP/5869*, House of Commons Library, February 2011, p 7.

“compensation for being disabled” and that DLA payments would be stopped if the recipient started work (discussed in more detail below).<sup>20</sup>

25. DWP also highlighted that there was a high level of “speculative claims” and that “a high proportion of claims are being made with little or no chance of succeeding”.<sup>21</sup> The Minister’s view was that this high disallowance rate suggested that many applicants knew little about DLA before they claimed and that many claims were “nugatory”.<sup>22</sup> She argued that the disallowance rate of around 55% indicated that large numbers of people without a basic level of eligibility were applying because “there is such a vague notion of who is eligible for DLA that many will apply just to see whether they are eligible.”<sup>23</sup> However, it should also be borne in mind that a significant number of people who might be eligible for DLA do not currently claim it.<sup>24</sup>

26. Claudia Wood of Demos agreed with the Government that the high disallowance rate suggested that people did not have a clear understanding of whether they ought to be applying. Sue Royston of Citizen’s Advice concurred.<sup>25</sup>

27. However, several witnesses took issue with this argument. Professor Roy Sainsbury, of the Social Policy Research Unit, University of York, pointed out that many claims which were initially disallowed were reconsidered or ultimately taken to appeal, where there was a 40% success rate.<sup>26</sup> Inclusion London suggested the reason for the high disallowance rate was that the DLA eligibility criteria are actually quite rigorous.<sup>27</sup> The Motor Neurone Disease Association (MNDA) and Citizens Advice Scotland both believed that DLA is well understood as a non means-tested, non-taxable cash benefit paid in recognition of the extra costs incurred by disabled people. Indeed, MNDA reported that it was the best understood benefit amongst its members.<sup>28</sup>

28. DWP has stated that DLA is complex to claim, with the application form coming in for particular criticism as being “long and overly repetitive”.<sup>29</sup> Several witnesses agreed that the claim form was too long and complicated and needed to be simplified.<sup>30</sup> Creative Support felt the form was “extremely long” and reported that it left claimants feeling “confused, degraded and upset”.<sup>31</sup> Macmillan Cancer Support stated that applicants found the claim

20 Department for Work and Pensions, *Disability Living Allowance and work: Exploratory research and evidence review*, RP 648, 2010, p 47.

21 Ev 96 and Department for Work and Pensions, *Disability Living Allowance Reform*, Cm 7984, December 2010, para 16.

22 Q 178

23 Q 186

24 Q 10

25 Q 5

26 Q 97

27 Ev w27 [Note: References to Ev wXX refer to written evidence published in the volume of additional written evidence on the Committee’s website.]

28 Citizens Advice Scotland, Ev w40 and Motor Neurone Disease Association, Ev w64

29 Ev 95

30 See, for example, TUC, Ev w10; Creative Support, Ev w23; and Citizens Advice Scotland, Ev w40

31 Ev w23

form “lengthy, repetitive, ambiguous and irrelevant to their circumstances”.<sup>32</sup> Citizens Advice Scotland noted that DLA is the single biggest issue dealt with in their bureaux, describing the process of claiming DLA as “a complex maze”.<sup>33</sup> Essex Coalition of Disabled People (ECDP) described DLA as a benefit “shrouded in uncertainty” and Citizens Advice told us that helping clients to complete the claim form takes between two and four hours and involves detailed exploration of their daily lives and consideration of how their needs fit with definitions in current case law. It agreed that the complexity of DLA needed to be addressed.<sup>34</sup>

### **Lack of a rigorous system of award reviews**

29. DLA may be awarded for a fixed period or indefinitely. DWP *ad hoc* analysis shows that of all DLA awards as at August 2010, 29% were for a fixed period and 71% were indefinite.<sup>35</sup> DWP referred to evidence from the 2004–05 National Benefit Review, which found that around £630 million was being overpaid (11% of cases) and around £190 million was being underpaid to claimants as a result of unreported changes in circumstances. It also noted that 24% of working age DLA claimants had either not had a change to their award, or their award looked at, for a decade.<sup>36</sup>

30. Professor Sainsbury acknowledged the scale of overpayments due to gradual changes in circumstances that went unreported. He pointed out that such cases are not included in the official figures for fraud and error as it would not have been reasonable to expect a claimant to have realised their circumstances had changed. Therefore, these cases are regarded as legally correct but are considered to be “technically incorrect”.<sup>37</sup> His view was that the way to deal with this problem was through reassessment.<sup>38</sup> Professor Steve Fothergill of the Centre for Regional Economic and Social Research, Sheffield Hallam University, felt it was “hard to argue against the regular reassessment of DLA claims”.<sup>39</sup>

31. Several witnesses agreed that a greater level of reassessment could be brought into the current DLA system. Professor Sainsbury did not believe there would be any “legal impediment” to DWP reassessing “the whole DLA caseload” if they chose.<sup>40</sup> Disability Alliance also took the view that reassessment of awards was already possible within the current system.<sup>41</sup>

32. However, the Minister told us that reform of DLA would have required amendments to primary legislation.<sup>42</sup> DWP’s view was that reform of DLA within the existing legislative

32 Ev w112

33 Ev w40

34 Ev 58

35 Department for Work and Pensions, *Analysis of Disability Living Allowance: DLA Awards*, March 2011, table 3.

36 Ev 96

37 Department for Work and Pensions, *Fraud, Error and other Incorrectness in Disability Living Allowance: The Results of the Benefit Review of Disability Living Allowance*, 2005, para 5.4.

38 Q 9

39 Ev 93

40 Q 3, Professor Sainsbury; Q 5, Claudia Wood; Q 123, Paul Farmer

41 Q 124

42 The Social Security Contributions and Benefits Act 1992.

framework would just mean “bolting on” additions to “an outmoded system”. It had decided to introduce a new benefit because this “presented an ideal opportunity to start afresh, keeping the best elements of DLA that disabled people value, but bringing the benefit into the 21st century.”<sup>43</sup>

### **Misperceptions of DLA as an out-of-work benefit**

33. As we have noted, there is evidence that some recipients of DLA perceive it as an out-of-work benefit. Professor Sainsbury told us that there was some evidence that DLA could act as a barrier to work but there was also some evidence to suggest the opposite effect—that DLA can help people to gain and retain employment.<sup>44</sup> This latter view was reinforced to us by DLA recipients who contributed to our public meeting in Neath Port Talbot.

34. Some witnesses suggested that successive governments had contributed to the misperception by conflating DLA with other disability-related benefits, particularly out-of-work benefits such as Incapacity Benefits (IB) and Employment and Support Allowance (ESA).<sup>45</sup> The Chancellor of the Exchequer, for example, stated in his Budget statement that DLA reform would enable the Government “to afford paying this important benefit to those with the greatest needs, while significantly improving incentives to work for others.”<sup>46</sup> In her foreword to the December 2010 Green Paper, Maria Miller MP wrote:

Just as we are committed to providing unconditional support to those who are unable to work, we know that work is the best form of welfare for those who are able to do so. That’s why I want as many disabled people as possible to benefit from employment—it is not acceptable for anyone to be trapped in a cycle of dependency.<sup>47</sup>

Inclusion London argued that the Government was seeking to “blur the public perception of DLA” by talking of breaking dependence on benefits and the advantages of employment in the context of DLA.<sup>48</sup> DWP’s own qualitative research suggests that DLA may enable recipients to gain and retain employment.<sup>49</sup> Geoff Fimister of RNIB referred to his organisation’s findings which suggested that, although it could not be quantified, DLA could be a powerful reinforcement to people’s ability to take up and remain in work.<sup>50</sup>

35. Witnesses believed that much more could be done to improve communication of the message that DLA can be claimed both in and out of work. Paul Farmer of Mind felt that DWP’s contact with IB claimants during the reassessment for ESA was an opportunity clearly to communicate the “very important message” that DLA would not be lost if the claimant gained employment. He also believed that providers in the Work Programme, the

43 Ev 97

44 Q 2

45 See, for example, Inclusion London, Ev w27

46 HC Deb, 22 June 2010, col 173.

47 Department for Work and Pensions, *Disability Living Allowance Reform*, Cm 7984, December 2010, p 1.

48 Ev w27

49 Department for Work and Pensions, *The impact of Disability Living Allowance and Attendance Allowance: Findings from exploratory qualitative research*, RP 649, 2010, para 6.1.1.

50 Q 112



Government's contracted employment programme, could play a greater role in disseminating the message.<sup>51</sup>

36. DWP's Impact Assessment for PIP states that the new benefit will be "an opportunity to improve understanding of the benefit and communicate that support is available both in and out of work."<sup>52</sup> The Minister recognised that the media often conflate DLA with IB and ESA, which can "create some confusion". She told us the Government would work with disabled people and their representative organisations to ensure that the role of the new benefit is more clearly understood.<sup>53</sup>

### **Addressing rising caseload and expenditure**

37. As we have noted, HM Treasury's response to the threefold increase in DLA caseload and the near quadrupling of expenditure since it was introduced was to announce in the June 2010 Budget the Government's intention to introduce a new benefit with a new assessment for eligibility. Its assumption, drawing on "evidence from the Work Capability Assessment" (WCA), was that a new assessment for eligibility would reduce caseload and expenditure by 20%.<sup>54</sup> The WCA is an assessment of eligibility for Employment and Support Allowance (ESA), the new out-of-work benefit for people with disabilities and health conditions, introduced in 2008.

38. Professor Sainsbury said he was "at a loss" as to where the 20% figure came from. He could not understand how the impact of the assessment on caseload could be predicted before any work had been done on the criteria and thresholds for the benefit. He could only understand the figure as a savings target.<sup>55</sup> Disability representative organisations also commented that the Government had not presented any robust evidence to support their assumption of a 20% reduction in caseload and expenditure. Scope believed that "this decision is based purely upon budgetary targets, rather than on robust evidence as to how the benefit is used and by whom".<sup>56</sup> The Government's position is that the 20% reduction is an assumption not a target. It also points out that "Due to forecast growth in working-age DLA expenditure, reducing working-age DLA expenditure by 20% in 2015/16 means returning working-age DLA expenditure to 2009/10 levels in real terms".<sup>57</sup>

39. Professor Fothergill pointed to previous problems with estimating the likely impact of new assessments for benefits, using the Government's own example of the WCA. In 2009 the Government predicted that 15% of Incapacity Benefit claimants would be found ineligible for ESA.<sup>58</sup> Official statistics show the actual figure in the reassessment trial was 32% (although it should be noted that this does not take account of the outcome of

51 Q 113

52 Department for Work and Pensions, *Disability Living Allowance Reform: Impact Assessment*, February 2011, p 1.

53 Q 232

54 HM Treasury/HM Revenue and Customs, *Budget 2010 Policy Costings*, p 36.

55 Q 39

56 Scope, *The Future of PIP: a social model-based approach*, October 2011, p 3.

57 Department for Work and Pensions, *Disability Living Allowance Reform – Impact Assessment*, October 2011, Summary: Analysis and Evidence. See also HC Deb 28 March 2011, col 3.

58 HC Deb, 20 October 2009, col 1347W.

appeals).<sup>59</sup> His view was that this was a “salutary lesson” and that the 20% estimate for DLA savings “could turn out to be 40%”.<sup>60</sup>

40. DWP referred to statistics on the rise in DLA caseload and expenditure from 2002–03 to 2010–11, published in July 2011. The headline figure from these statistics was a 29% increase in *total* DLA caseload (i.e. including children and over 65s as well as working-age claims) from just under 2.5 million in 2002–03 to around 3.2 million in 2010–11. DWP acknowledged that there were “several factors which could have increased the take-up of DLA”, including “maturing” of the benefit as more people over the age of 65 retain their DLA, and greater awareness of the availability of the benefit. However, it also argued that lack of clarity in DLA criteria and inconsistency in award decisions had led to a large proportion of appeals and a growing amount of case law. This in turn had “widened the interpretation of the eligibility criteria for DLA by increasing the number of different factors that may be taken into account, making the benefit less targeted and available to far more people than originally intended.”<sup>61</sup>

41. Witnesses objected to DWP’s emphasis on the headline figure of 29% growth in *total* DLA caseload. As noted above, DWP’s current reforms will apply only to *working-age* DLA claimants. The Disability Benefits Consortium and others argued that DWP’s own statistics show that “growth of working age [DLA caseload] was closer to 16% once demographic changes and population growth were taken into account.”<sup>62</sup>

**42. We accept the argument that DLA requires reform. There is some evidence that the benefit has insufficiently clear criteria and is not always well understood. The complex claim form can also make it difficult for people to make a claim. We therefore support the Government’s intention to address these issues.**

**43. There is not a proper system for reviewing DLA awards: 24% of working-age DLA claimants have either had no change in or no review of their award for over a decade. While official fraud and error levels are comparatively low, there is evidence that around 11% of awards may be overpaid due to changes so gradual over time that claimants could not be expected to report a change in circumstances. We accept that there needs to be an appropriate, consistent and clear system for reviewing awards.**

**44. Some witnesses believed that the necessary changes could have been made within the existing DLA structure. The Government’s view is that this would have required changes to primary legislation and that there are advantages to a “fresh start”. We agree that introducing a new benefit under a new legislative framework could offer the opportunity to improve support for disabled people while addressing the problems with DLA which the Government has identified. However, we believe the starting-point for reform should be to design a new benefit which meets its objectives in recognising the additional costs which disabled people incur. It is unfortunate that a background of**

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59 “Grayling: initial reassessments of those on IB in Aberdeen and Burnley show large numbers of claimants with the potential to return to work”, DWP Press Release, 10 February 2011.

60 Q 43

61 Ev 96

62 Ev 62

budget cuts has created unnecessarily high levels of anxiety about this reform amongst DLA recipients.

45. We are also concerned that the Government is basing its assumptions for the scope for reducing working-age caseload on the fact that there was growth of 29% in total DLA expenditure between 2002–03 and 2010–11. It is important to bear in mind that a substantial part of this growth arises from demographic change, including the increase in the number of people over state pension age who retain their DLA. PIP will only apply to working-age claimants, where growth is closer to 16% after taking account of demographic changes. We would welcome clarification from the Government on how these statistics can be reconciled with the savings assumption, in response to this Report.

46. We explore the extent to which the design of PIP is likely to lead to a more effective benefit in the remainder of this report.

## 3 Consultation, communications and media coverage

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47. The Government has described the task of communicating its proposed reforms as “challenging”. DWP notes that “the target audiences are large and complex and their requirements, understanding and behaviours are very diverse.” However, it has pledged to put disabled people “at the heart of the development of the new benefit”.<sup>63</sup> In this chapter we examine the effectiveness of the Government’s consultation and its communications strategy. We also consider its role in encouraging accurate media coverage of the reforms and of disability issues more generally.

### Media reporting on disability benefits

48. In our 2011 Report on the migration of claimants from Incapacity Benefits to ESA we expressed concerns about the way the media reported on benefit issues and how official statistics were interpreted by the media. We highlighted that sections of the media routinely use pejorative language when referring to benefit claimants. We believed this to be irresponsible and inaccurate. We fully accepted that the Government does not control the nature and content of media coverage but felt that extreme care was needed in the way the Government engaged with the media and in particular the way in which it releases and provides its commentary on official statistics. We said that the Government should take great care with the language it uses and take all possible steps to ensure that context is provided when information is released, so that unhelpful and inaccurate stories can be shown to have no basis.<sup>64</sup> This need for the Government to exercise care applies equally to press coverage of DLA reform as to Incapacity Benefit reform.

49. Some witnesses identified similar problems with the reporting of statistics relating to DLA as has occurred with ESA. The Disability Benefits Consortium believed that “misuse and misreporting of statistics” was leading to anxiety amongst disabled people.<sup>65</sup> Mental health organisations wrote that:

We are concerned that the Government has not sought to publicly correct the significant amount of media coverage of DLA in recent months which has portrayed the benefit as a “handout” for people with minor ailments such as allergies; has suggested that very little evidence is needed to claim the benefit; and has falsely suggested that being on the benefit means you don’t have to work.<sup>66</sup>

Amanda Batten of the National Autistic Society urged the Government to provide more “explanatory notes and context” with its statistical releases.<sup>67</sup>

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63 Ev 106

64 Work and Pensions Committee, Sixth Report of Session 2010–12, *The role of incapacity benefit reassessment in helping claimants into employment*, HC 1015, para 40–41.

65 Ev 66

66 Ev 56

67 Q 172

50. Reporting of recent DWP statistics relating to the use of evidence in decision-making for new DLA claims in 2010 demonstrated the problem. The DWP paper showed that 16% of decisions were made on the basis of the claim form; 42% were made following a GP's report; 6% following a face-to-face assessment; and 36% on the basis of "other" sources of evidence. The paper makes clear that "more than one piece of further evidence can be used to make the decision" and that the figures "indicate the evidence which the Decision Maker considered to be the main source used to make the decision."<sup>68</sup>

51. The *Daily Mail* reported the statistics under the headline "Disabled Benefit? Just fill out a form" and stated that "A staggering 94 per cent of new claimants for Disability Living Allowance started receiving their payments after only filling out paperwork."<sup>69</sup> The *Daily Telegraph* headline was "£300 million of disability benefits paid 'without checks'".<sup>70</sup> The articles included a quotation from the Secretary of State for Work and Pensions: "At the moment, hundreds of millions of pounds are paid out in disability benefits to people who have simply filled out a form." However, the statistics were released without any official DWP press release.

52. The Minister for Disabled People told us that DWP releases a great deal of statistics in an attempt to be transparent and to aid people's understanding of the "facts and figures". She defended the Department's approach to statistical releases:

We have an excellent press department that provides context for people who contact us, but it requires people to contact us to be able to give them the context in which those data might be best viewed. It is very difficult for us to control the way the media choose to interpret information. Obviously, we would always do everything we can to ensure that information is put out there in the right context.<sup>71</sup>

The Minister also implicitly defended the media's approach, suggesting the "deeper point" was that they were reflecting the public's lack of confidence in the integrity of the benefits system.<sup>72</sup> We received a similar response in the Government's reply to our Report on the Incapacity Benefits migration, where the Government said more than once that "The Committee and Government need to be mindful of widespread public unease about the number of people claiming incapacity benefits, so it is not surprising to see that reflected in the media."<sup>73</sup>

**53. The Government's view seems to be that the negative tone of press coverage of benefit claimants is unsurprising since it merely reflects the public mood about the integrity of the benefits system. However, the Government should not ignore the fact that public opinion can also be positively influenced by the media and we believe it**

68 Department for Work and Pensions, *DLA Award Values and Evidence Use for New Claims in 2010, in Great Britain*, November 2011, p 6.

69 *Daily Mail*, 11 November 2011.

70 *The Telegraph*, 11 November 2011.

71 Q 236

72 *Ibid.*

73 Work and Pensions Committee, Seventh Special Report of Session 2010-12, *The role of incapacity benefit reassessment in helping claimants into employment: Government Response to the Committee's Sixth Report of Session 2010-12*, HC 1641, pp 2 and 5.

should take the necessary steps to ensure that its own contribution to media stories about benefits is accurate and contextualised.

54. While we accept that the Government does not control the editorial line taken by the media, we believe it should actively encourage accurate reporting of its own statistics on benefits. Direct quotations from Ministers can give undue credence to inaccurate or misleading reports. We recommend that DWP establishes internal protocols to ensure that significant statistical releases are accompanied by a press release setting out the context and providing background explanatory notes, together with quotations from Ministers where appropriate.

55. Witnesses also highlighted the negative tone adopted in the media about wider disability issues.<sup>74</sup> Amanda Batten of the National Autistic Society cited a recent report by the University of Glasgow’s Strathclyde Centre for Disability Research, which looked at changes in the way the print media report disability issues and its impact on public attitudes towards disabled people.<sup>75</sup> The report found a significant increase in reporting of disability from 2004–05 to 2010–11 and an increased “politicisation” of coverage over the same period. There had been a reduction in the proportion of articles which reported disability sympathetically. People with mental health problems and other “hidden” disabilities were particularly likely to be represented as “undeserving”. Reporting of disability benefit fraud had increased and this had impacted on people’s perceptions of disability benefits. Focus groups perceived fraud levels to be much higher than they were in reality; some participants suggested that 70% of disability claims were fraudulent and justified this claim by reference to newspaper articles. The report also found a significant increase in the use of pejorative language to describe disabled people—use of terms such as “scrounger” and “cheat” were found in 18% of articles about disability issues in 2010–11, compared to 12% in 2004–05.<sup>76</sup>

56. Amanda Batten told us that these negative public perceptions meant that disabled people were facing practical difficulties such as people being unwilling to help them. Disability Alliance felt the debate about disability benefits had been set in the context of “benefit claimants versus the taxpayer”, ignoring the fact that disabled people make a contribution to society, often as taxpayers themselves.<sup>77</sup>

### **Proposed new UK Disability Strategy**

57. On 1 December 2011 the Government published a discussion document which “sets out the Government’s vision of enabling disabled people to fulfil their potential and have opportunities to play a full role in society”. It contains three areas for discussion: realising aspirations; increasing individual control; and changing attitudes and behaviours. There will be a three-month consultation period on these issues, before the Government publishes its new UK Disability Strategy in the spring.<sup>78</sup> The Minister told us the new UK

74 Qq 172–173, Amanda Batten, Eugene Grant, Geoff Fimister and Neil Coyle

75 Q 172

76 University of Glasgow Strathclyde Centre for Disability Research and Glasgow Media Unit, *Bad News for Disabled People: How the newspapers are reporting disability*, November 2011.

77 Q 173

78 HC Deb, 1 December 2011, col 78WS.

Disability Strategy would be an opportunity both to improve understanding of disability and to help disabled people make a contribution.<sup>79</sup>

**58. We look forward to the publication of the new UK Disability Strategy. It provides an opportunity to address the apparent growth in negative perceptions about disability. We recommend that it contains proposals to tackle negative reporting of disability in the media and a Government strategy to get the message across that disabled people can and do make a positive contribution to society, very often as taxpayers.**

### **DWP consultation and communications strategy**

59. DWP has pledged to “put the disabled person at the heart of the development of the new benefit and the claim process.” Following the Chancellor of the Exchequer’s announcement of plans to reform DLA, DWP consulted informally with disabled people and disability representative organisations prior to publication of its Green Paper in December 2010. These initial discussions included early development of the new assessment with an independent group of specialists in health, social care and disability, and included disabled people. DWP stated that it would inform and consult with disabled people and their representative organisations throughout the policy development process. It was committed to ensuring that “disabled people have a genuine opportunity to influence and shape the detailed design.”<sup>80</sup> The Minister told us that the Government was “very much committed” to “co-production” of the new benefit.<sup>81</sup>

60. There were mixed views from disability organisations about the consultation process and their ability to influence it. While Geoff Fimister of RNIB noted that DWP officials had been “pretty accessible”, Neil Coyle of Disability Alliance felt that, in the 12 months following the June 2010 Budget announcement, consultation “was not bearing any fruit at all”. His view was that the Government had not offered any rationalisation for a 20% reduction in expenditure and had “totally ignored” the potential consequences of reform for current working-age DLA recipients. He also argued that the Government had not taken on board the views of disability organisations in the development of the Welfare Reform Bill, which was published before the end of the DLA consultation period. Disability Alliance had issued a letter of claim to DWP, outlining its legal case for judicial review of the Bill.<sup>82</sup>

61. A recent report, *Responsible Reform*, researched and written by disabled people who had come together through social media, argued that DWP had misrepresented the strength of feeling against DLA reform expressed in responses to the consultation. The report analysed over 500 responses which had been submitted by organisations (out of a total of 5,500) and which were released by DWP under a Freedom of Information request. It found an overwhelming majority against specific measures, such as: the change to two rates of PIP daily living (92%); extension of the qualifying period (98%); and introduction of a new assessment (90%). It concluded that DWP’s response to the consultation had

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79 Q 238

80 Ev 106

81 Q 235

82 Q 165, Geoff Fimister; Qq 168–170, Neil Coyle, a Labour Councillor in the London Borough of Southwark

failed properly to take these views into account.<sup>83</sup> However, the Minister for Disabled People, responding to a Parliamentary Question, said the report seriously misrepresented DWP's approach to the DLA consultation and failed to acknowledge the "extensive work" the Department had done since the consultation had ended.<sup>84</sup>

62. Paul Farmer of Mind echoed Geoff Fimister's view that communications with DWP, in the later stages of the policy development process, had improved. However, he felt that communications had "not been handled well" in the early stages. The Chancellor's June 2010 Budget Statement had set the reforms firmly in the context of expenditure reduction in the current economic downturn, with little information about the rationale for the reforms or the potential impacts.<sup>85</sup>

**63. The Chancellor of the Exchequer's announcement of the intention to reform DLA made the Government's communications task a difficult one. This difficult beginning was compounded by the poor initial consultation on the Green Paper which was not only shorter than recommended by the Government's own Code of Practice on Consultation but also took place over the Christmas period. The Bill was published before the consultation period ended, and well before the responses could be analysed. The Government's published response appeared not to reflect the full extent of respondents' concerns, and the full responses were not published.**

**64. Since then, DWP has taken steps to involve disabled people in the process for devising and implementing PIP and this has proved to be effective to some extent. The Department has listened to many concerns: it dropped the proposals to end payment of the DLA mobility component for care home residents after the Low Review and to extend the three-month qualifying period under DLA to six months under PIP. It is important that DWP now puts even more effort into engaging disabled people in the introduction of PIP and that it clearly demonstrates the extent to which it has responded to their legitimate concerns.**

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83 Dr S. J. Campbell et al, *Responsible Reform: A Report on the proposed changes to Disability Living Allowance*, January 2012.

84 HC Deb, 20 January 2012, col 1022W.

85 Q 167



## 4 Assessment of the impacts of the introduction of PIP

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65. A key criticism levelled at the Government by disability organisations is that it has failed properly to assess the potential impacts of its reforms. This chapter examines some of the potential impacts and the Government’s approach to assessing them. The impact on current working-age recipients of DLA reform is not limited to possible loss of DLA alone; we considered the cumulative impacts of DLA reform together with Incapacity Benefit reform, loss of “passported” benefits and services, and the potential knock-on impacts on NHS and local authority care budgets.

### DLA mobility component for residents of publicly funded care homes

66. In the October 2010 Spending Review, the Government announced its intention to align the rules for the mobility component of DLA in relation to care home residents with those for the DLA care component, by withdrawing it from residents of publicly-funded care homes after 28 days. This was scheduled to come into force from October 2012.<sup>86</sup> The Government argued the measure was necessary in order to prevent DLA being paid where people’s mobility needs were already being met by care home providers.<sup>87</sup>

67. In response to strong opposition from disability representative organisations, the Government gave a commitment not to remove the DLA mobility component from people in residential care in 2012, but to consider the measure as part of the wider reform of DLA.<sup>88</sup> However, a clause in the current Welfare Reform Bill, making provision for Regulations to withdraw the mobility component from care home residents on the introduction of PIP from 2013, remained in place while the Government looked again at the evidence.<sup>89</sup>

68. In July 2011, Mencap and Leonard Cheshire Disability launched their own review of personal mobility for those in publicly-funded residential care. The review, chaired by Lord Low of Dalston, a cross-bench Peer and longstanding disability-rights campaigner, consulted for 12 weeks and received over 800 submissions from individuals, disabled people’s organisations, disability charities, residential care providers, and local authorities. It also held 13 oral evidence sessions with a range of witnesses, including our Committee Chair.<sup>90</sup> The Low Review reported on 3 November 2011. The Report identified “a lack of consistency over responsibility for mobility in local authority responses” showing “the need for clear guidance to local authorities when it comes to funding mobility needs and the role played by DLA mobility.” It concluded that there was “no evidence of a duplication

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86 HM Treasury/Department for Work and Pensions/HM Revenue and Customs, *Spending Review 2010 policy costings*, p 10.

87 Ev 98–99

88 Department for Work and Pensions, *Government’s response to the consultation on Disability Living Allowance Reform*, Cm 8051, April 2011, pp 40–41.

89 Welfare Reform Bill, clause 84 [HL Bill 114 (2010-12)].

90 *The Low Review: Independence, Choice and Control — DLA and personal mobility in state-funded residential care*, November 2011, pp 10 and 11. For full details see <http://lowreview.org.uk/>

of funding in relation to the mobility needs being met by local authorities and those being met by DLA mobility.”<sup>91</sup>

69. On 1 December, DWP announced it would not remove the mobility component from care home residents as there was “insufficient evidence of overlaps in funding”. It gave a commitment to table an amendment to leave out the relevant clause from the Welfare Reform Bill and this was subsequently agreed at Report stage in the House of Lords.<sup>92</sup>

70. The Minister paid tribute to the work of the Low Review. She told us that, although there was “a very clear theoretical overlap” between support provided through social care and that provided through DLA, the Low Review and DWP’s own research had shown that the evidence for financial overlaps was, in practice, “patchy”. DWP had listened to people’s “very real concerns” about the Spending Review announcement, at which point it had “looked immediately at what was happening in practice”. The Minister acknowledged that this was “not the ideal order in which to do it”.<sup>93</sup>

**71. We welcome the Government’s decision not to proceed with its plans for withdrawal of the DLA mobility component from residents of publicly-funded care homes. We congratulate all involved in Lord Low of Dalston’s review, which established a lack of evidence for the measure and a need for clear guidance to local authorities. We recommend that the Government now issues clear guidance about funding mobility needs and the role played by DLA and PIP mobility. We believe that this sequence of events clearly demonstrates the need for the Government to conduct thorough research, including detailed impact assessments, before the announcement of measures that could have a negative impact on disabled people. However, we accept that the Government listened to the representations of those affected.**

## **Potential knock-on impacts on NHS and local authorities’ care budgets**

72. The Government does not believe that withdrawal of DLA from a proportion of current working-age recipients will place greater demand on the NHS and local authorities’ social care budgets because “access to support services through the NHS and Local Authorities is not dependent on receipt of DLA” and it “expects individuals who require these services to be accessing them already”. DWP also noted that DLA is part of a broader package of support available to disabled people, including Work Choice (a specialised contracted employment programme), the Disabled Facilities Grant (a means-tested grant, available from local authorities, towards the cost of adapting homes) and the Supporting People programme (housing support for older and disadvantaged people available through local authorities via a central government grant). DWP’s view was that these programmes already provide alternative sources of support.<sup>94</sup>

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91 “Lord Low’s review urges Government to save mobility payments for disabled people living in residential care”, Low Review press release, 3 November 2011.

92 HC Deb, 1 December 2011, cols 77–78WS.

93 Q 214

94 Ev 98

73. However, disability organisations argued that many disabled people were not eligible for this alternative support and highlighted the unique nature of DLA as the only universal benefit specifically designed to contribute towards the extra costs of disability.<sup>95</sup> The Disability Benefits Consortium emphasised that DLA played a particularly important role in helping people to manage their conditions and reducing recipients' need for NHS and social care services. Respondents to its survey on DLA had reported that loss of DLA would impact on their ability to manage conditions in a variety of ways, including paying for travel to and from medical appointments, prescriptions, heating and food. The survey included testimony from survey respondents who raised concerns that loss of DLA could lead to deterioration in health, which in turn could increase demand for NHS and local authority services.<sup>96</sup> Mental health organisations argued that it was “extremely short-sighted” and “incompatible with the NHS emphasis on prevention” potentially to allow conditions to deteriorate to the point where “it is more complicated and expensive to facilitate someone’s recovery”.<sup>97</sup>

74. Simon Dawson of DWP told us that the current practice of allowing local authorities to charge for their care services against receipt of individuals' disability-related income, including DLA, would continue under PIP in the same way. However, we wanted to know whether the Government had considered the impact on local authorities if people who received care services, paid for from their DLA, were found ineligible for PIP, leaving local authorities to pick up the shortfall in their charges. The Minister did not seem to believe that there would be any risk to local authority budgets because those who needed social care were very likely to qualify for PIP. We put it to her that a risk *would* exist because there was no guarantee that DLA claimants who were social care users would be found eligible in the new and potentially more rigorous PIP assessment, which would be based on different criteria to the local authority social care assessment. However, the Minister maintained her position, insisting that those found ineligible for PIP were unlikely to qualify for local authority social care.<sup>98</sup> The Local Government Association Social Security Advisors Group disagreed:

Any potential loss of benefit is likely to impact on the income of local authorities through a loss in revenue through charging. The situation will be exacerbated if fewer people qualify for PIP despite having been previously assessed for social care services.<sup>99</sup>

**75. We believe that the Government cannot fully assess the potential knock-on impacts of DLA reform on other providers of services for disabled people. There is evidence to suggest that DLA plays an important role in helping recipients to manage their conditions, thereby reducing the need for other services. If a DLA recipient is found ineligible for PIP, yet still needs support, we would not agree with the Minister that**

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95 See, for example, Disability Benefits Consortium, Ev 63 and Scope, Ev 79

96 Disability Rights Partnership, *End of a Lifeline? Ending Disability Living Allowance to introduce Personal Independence Payment: DLA Reform Consultation Response*, February 2011.

97 Ev 54

98 Qq 204–206

99 Ev w88

there is already an adequate alternative package of support available to all current working-age recipients of DLA who may be affected by these reforms.

76. DLA is unique in providing a universal benefit specifically designed to contribute to the extra costs of disability. If it is removed from some claimants who still have these extra costs, they are very likely to need to draw on services provided by other public agencies. We recommend that the Government carry out more detailed assessment of the wider impacts of DLA reform and consult further with local authorities and the NHS on the implications for their provision of services for disabled people, now that the updated impact assessment has been published.

### Passported benefits

77. Eligibility for DLA currently acts as a “passport” to a number of other DWP benefits, including Carers Allowance, and the Motability scheme. It also gives access to various benefits and services provided by other government departments, local authorities and the Devolved Administrations, such as: automatic qualification for a “Blue Badge” parking permit; eligibility for concessionary travel (free off-peak travel on local buses); exemption from Vehicle Excise Duty; eligibility for a driving licence at age 16 instead of 17; and exemption from payment for a medical examination for the purpose of obtaining an exemption from wearing seat belts.<sup>100</sup>

78. DWP acknowledged that receipt of DLA is currently an administratively simple way for local authorities and other bodies to establish entitlement to other benefits and services, obviating the need for “duplicate assessments”. It noted, for example, that over 850,000 people in receipt of higher rate DLA mobility component currently benefit from the automatic link to entitlement to a Blue Badge. DWP has stated that, in designing PIP, and the entitlements it will bring, it “will keep in mind the existing passporting arrangements with a view to maintaining them wherever possible”.<sup>101</sup> In November 2011, DWP stated that its intention was for both rates of the daily living component of PIP to act as a passport to Carers Allowance.<sup>102</sup>

79. The Disability Benefits Consortium reported “considerable anxiety” not only about Carers Allowance but also the range of other benefits and services to which DLA currently acts as a passport. It claimed the Government had “failed to assess how other passported benefits will be affected by DLA/PIP changes.”<sup>103</sup> The National Autistic Society pointed out that DLA recipients are passported to higher rates of ESA, Income Support, Jobseekers Allowance, Housing Benefit, Council Tax Benefit, Working Tax Credit and Child Tax Credit.<sup>104</sup> Citizens Advice also highlighted the importance of DLA as a passport to the disability premium of Working Tax Credit and was concerned that people currently on lower rates of DLA could lose support which makes “a quite significant difference” to their

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100 Ev 101

101 Department for Work and Pensions, *Personal Independence Payment – Policy briefing note: Passporting from Personal Independence Payment*, May 2011, para 6.

102 Department for Work and Pensions, *Personal Independence Payment – Policy briefing note: Passporting from Personal Independence Payment*, November 2011, para 7.

103 Ev 65

104 Ev 86

incomes.<sup>105</sup> It should be noted that the household benefit cap which is being introduced under the Welfare Reform Bill will not apply to households which contain a member, including a child, who is a DLA or PIP recipient.<sup>106</sup>

80. DWP's intention is that a PIP award letter will confer eligibility for passported benefits in the same way as DLA. It told us that it would ensure all Government departments and external bodies were aware of the introduction of PIP so they could amend their systems accordingly. Its intention was that people with "the greatest barriers to participation" would be able to access passported services and benefits "as easily as possible".<sup>107</sup> The Minister told us DWP was working with a "cross-Whitehall Personal Independence Working Group" to consider interaction between PIP and passported benefits and services provided by other departments. However, she believed that it was for other departments to decide how entitlement to their own benefits and services was established and whether PIP would be the most appropriate gateway.<sup>108</sup>

### Cumulative impacts of DLA and IB reform

81. Around 74% of working-age DLA recipients also claim Incapacity Benefits (IB)—out-of-work benefits for people with health conditions and disabilities.<sup>109</sup> IB claimants are currently being migrated onto a replacement benefit, Employment and Support Allowance (ESA), which was introduced for new claims from October 2008. The current Government began a reassessment of all existing IB claimants in 2011; its intention is that 1.5 million claimants will be reassessed by 2014.<sup>110</sup> In trials of the reassessment undertaken in Aberdeen and Burnley, 32% of participants were found "fit for work" and therefore ineligible for ESA (although this figure does not reflect the outcome of appeals).<sup>111</sup>

82. Professor Fothergill's view was that the PIP proposals would have the greatest impact on those who are out of work and who use DLA primarily as a supplement to Incapacity Benefits/ESA. He predicted that many of these people would experience a "double whammy" effect from DLA and IB reform. He argued that households in receipt of both DLA and IB were able "to sustain a lifestyle just above the poverty line" but that the combination of DLA and IB reform would close off this option for many.<sup>112</sup> A recent report by the Centre for Regional Economic and Social Research, co-authored by Professor Fothergill, concluded that by 2014 IB reforms will cut caseload by "nearly one million" and that "nearly 600,000" IB claimants will be taken out of the benefits system entirely.<sup>113</sup>

105 Q 37

106 Department for Work and Pensions, *Household Benefit Cap Equality Impact Assessment*, October 2011, para 4.

107 Ev 101

108 Q 207

109 Department for Work and Pensions, *DLA claimants—a new assessment: The characteristics and aspirations of the Incapacity Benefit claimants who receive Disability Living Allowance*, Research Report 585, 2009, para 2.1.

110 See Work and Pensions Committee, Sixth Report of Session 2010-12, *The role of incapacity benefit reassessment in helping claimants into employment*, HC 1015.

111 "Grayling: initial reassessments of those on IB in Aberdeen and Burnley show large numbers of claimants with the potential to return to work", DWP Press Release, 10 February 2011.

112 Ev 93

113 Beatty and Fothergill, *Incapacity Benefit Reform: The local, regional and national impact*, Centre for Regional Economic and Social Research, November 2011.

83. Citizens Advice believed that the group most likely to lose out in the PIP reforms were those with significant but not severe disabilities or health conditions, who were most at risk of being found ineligible. It argued that, although these people had less acute conditions, they did not necessarily have lower disability-related costs. It shared Professor's Fothergill's view that the same people were most likely to lose out in the IB reforms. It saw this as "the single most important issue" in DLA reform.<sup>114</sup>

84. The Minister for Disabled People told us DWP was "very conscious" of the combined impacts of IB and DLA reforms and it was "looking very closely" at what the impacts were likely to be. However, she said it would not be possible to assess the impacts until the details of PIP had been finalised.<sup>115</sup>

### Structural change from three rates of DLA care to two of PIP daily living

85. DWP plans to address the complexity of DLA in part by having just two rates (standard and enhanced) of each PIP component (daily living and mobility). This will reduce the number of possible rate combinations from 11 to 8. The structural change is also designed to more clearly separate the criteria for each component. DWP pointed out that the DLA lower rate mobility criteria refer to the need for "supervision or guidance when outdoors" and the care component "is largely based on the need for supervision or attention".<sup>116</sup>

86. The Government's Impact Assessments published in February and October 2011 did not include an estimate of the number of people likely to lose support in the reforms. The October Impact Assessment (IA) set out the number of people in receipt of each combination of DLA "to provide an indication of the people who could potentially be affected by the policy":<sup>117</sup>

	Higher Rate Mobility	Lower Rate Mobility	No Mobility Rate
Highest rate care	509,000	178,000	45,000
Middle rate care	461,000	476,000	116,000
Lowest rate care	420,000	208,000	253,000
No care rate	389,000	102,000	—

The IA stated that estimates of the impact on current working-age DLA recipients would only be possible once more of the detailed design of the PIP assessment had been completed.<sup>118</sup>

87. Disability organisations were concerned that the change to two rates of the PIP daily living component would mean current recipients of lower rate DLA care were likely to lose the benefit. The Disability Benefits Consortium (DBC) estimated that the number of people affected could be at least 652,000 and it was concerned that the total number could

114 Ev 58

115 Q 201

116 Ev 97

117 Figures from Department for Work and Pensions, *Longitudinal Survey*, May 2010.

118 Department for Work and Pensions, *Disability Living Allowance Reform Impact Assessment*, October 2011.

be over 750,000 if HM Treasury's assumption of a 20% reduction in caseload was realised.<sup>119</sup> The DBC was "alarmed" by the potential impact of loss of support on disabled people's ability to meet "basic daily costs", including: "higher utility bills; medical and equipment costs not faced by non-disabled citizens; dietary costs; higher travel expenditure and other essentials for everyday life."<sup>120</sup> It cited a recent survey of 2,286 people, 80% of whom were current DLA recipients, by the Papworth Trust, which found that: "Three-quarters of disabled people would not have enough money if their DLA were cut. 6 in 10 would lose some of their independence [and] 86% of disabled people would cut back on essentials like food and transport if their DLA were cut."<sup>121</sup> Responses to a Disability Rights Partnership survey of 1,700 people, 82% of whom were in receipt of DLA or caring for a DLA recipient, included concerns that loss of part or all DLA support would lead to "poverty and exclusion" or even consideration of suicide.<sup>122</sup>

88. DWP described concerns that many recipients of lower rate DLA care would lose the benefit under PIP as "simply speculation". In September 2011 it stated it was "too early to make any evidence-based assessment of the impact of the reforms on the existing DLA caseload". It promised more information "in the autumn", after completion of initial testing of the draft PIP criteria (see chapter 5, below).<sup>123</sup> Such information had not been published before we heard oral evidence from the Minister for Disabled People on 12 December 2011. The Minister told us that DWP was still assessing the results of the testing, in consultation with disability representative organisations, to ensure the PIP eligibility criteria work in a fair and consistent way.<sup>124</sup> DWP expected to be able to publish its estimate of the number of people likely to be affected "in the next few weeks". The Minister repeated her assurance that it would be published before the relevant Report Stage debate in the House of Lords, scheduled for January 2012.<sup>125</sup> In the event it was published on the day before the debate, on 16 January.<sup>126</sup>

89. Disability Alliance was "hugely disappointed" that DWP's estimate was not published in the autumn as promised. It stood by its claim that recipients of the DLA lower rate care component would be the main losers, which it said had been arrived at in a "vacuum" of official information. It asserted that DWP's intention to focus resources on "those with the greatest needs", the structural change to only two rates of PIP daily living component and HM Treasury's assumption of a 20% reduction in caseload, "make it highly likely existing DLA low rate care recipients are very much at risk of losing support under PIP".<sup>127</sup>

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119 Ev 63

120 Ev 62

121 Papworth Trust, *Disability Living Allowance Changes: Survey Results*, September 2011.

122 Disability Rights Partnership, *End of a Lifeline? Ending Disability Living Allowance to introduce Personal Independence Payment: DLA Reform Consultation Response*, February 2011.

123 Ev 98

124 Q 193

125 Qq 199–200

126 Department for Work and Pensions, *Personal Independence Payment: assessment thresholds and consultation*, 16 January 2012.

127 Ev 67

90. The additional information published by DWP on 16 January 2012 included proposed entitlement thresholds for PIP. As noted, this met the commitment to make the information available prior to the Report Stage debate on PIP in the House of Lords on 17 January, but was too late for us to consider before we took evidence from the Minister.

91. Drawing on data from the trial assessments of 937 people carried out in summer 2011, and using the newly proposed entitlement thresholds (see chapter 6), DWP estimated that the PIP assessment criteria as drafted would produce a working-age caseload of 1.7 million in 2015–16. Without the introduction of PIP, working age DLA caseload was forecast to be 2.2 million. This represents a projected caseload reduction of around 23%.

92. The DWP paper outlines claimant case studies, describing the circumstances of 15 illustrative PIP claimants, the scores they would attain for each activity descriptor in the assessment and the rate to which they would be entitled in each component. Examples given include those who would not be entitled to either component of PIP. The case studies do not state whether the claimants would have been entitled to DLA or at which DLA rate combination. It is also not possible to ascertain, from the way the projected caseloads are set out in the paper, from which rate combinations of DLA the working-age PIP caseload reduction of 500,000 will come. The projected 2015–16 working-age caseloads for DLA, i.e. without the current reforms, and those for PIP are set out below.<sup>128</sup>

### ***Breakdown of forecasted DLA case by rate combination***

<b>2015–16: 16–64 age DLA rate combination</b>	<b>Caseload</b>
Higher rate mobility, higher rate care	350,000
Higher rate mobility, middle rate care	290,000
Higher rate mobility, lowest rate care	270,000
Higher rate mobility, no care	130,000
Lower rate mobility, higher rate care	170,000
Lower rate mobility, middle rate care	450,000
Lower rate mobility, lower rate care	230,000
Lower rate mobility, no care	50,000
No mobility, higher rate care	10,000
No mobility, middle rate care	40,000
No mobility, lower rate care	190,000
<b>Total</b>	<b>2,200,000</b>

<sup>128</sup> Department for Work and Pensions, *Personal Independence Payment: assessment thresholds and consultation*, January 2012, tables 1 and 2.



### ***Breakdown of eligible PIP caseload by Daily Living and Mobility component combination***

<b>2015–16: PIP rate combination</b>	<b>Caseload</b>
Enhanced mobility rate, enhanced daily living rate	340,000
Enhanced mobility rate, standard daily living rate	190,000
Enhanced mobility rate, no daily living	230,000
Standard mobility rate, enhanced daily living rate	110,000
Standard mobility rate, standard daily living rate	250,000
Standard mobility rate, no daily living	190,000
No mobility rate, enhanced daily living rate	90,000
No mobility rate, standard daily living rate	250,000
<b>Total</b>	<b>1,700,000</b>

93. DWP has described other organisations’ projections of the likely impact of DLA reform as “simply speculation”. However, accurate analysis by interested bodies has been extremely difficult and claims have been made devoid of any factual basis in the absence of DWP impact assessments. Until very recently, the information released by the Government included no estimate of the number of people likely to be affected or any scenario modelling to indicate the likely impacts on different groups.

94. The fact that Government information has been released at a late stage, and the consequent “speculation” by interested bodies, has also exacerbated public concern about the likely impacts of the introduction of PIP and worked against the Government’s aim of reassuring disabled people that reform is intended to be a positive step for them. It is important that the Government and interested bodies learn from this. In future, major benefit reform proposals should be accompanied by detailed and comprehensive analysis of the likely impacts as soon as practicable.

95. We are unable to ascertain, from the latest figures released by DWP in January, from which DLA rate combinations the projected PIP caseload reduction of 500,000 claimants will come and therefore which current DLA recipients are likely to have their benefit withdrawn altogether. We recommend that, in its response to this Report, DWP sets out further case studies to show how the introduction of PIP is likely to affect current working-age recipients of each rate combination of DLA.

### **Extending the Required Period Condition**

96. DLA is not payable until a claimant has met the eligibility criteria for at least three months (the “qualifying period”) and is expected to continue to meet the criteria for at least a further six months (the “prospective test”). These periods together make up a Required Period Condition (RPC) of nine months, designed to focus the benefit on people with long-term health problems and disabilities.

97. The Government originally proposed to extend the PIP RPC to 12 months by increasing the qualifying period from three to six months. DWP’s “principal aim” in doing so was to “align the definition of long term disability with the Equality Act 2010.” It did not expect the measure to provide “any significant savings”. DWP argued that “although some conditions appear long-term at their outset and additional costs may arise as a result, this may not always be the case.” It maintained that:

[...] where disability-related costs do arise early on, for instance as a result of having to make frequent hospital visits for treatment, additional support mechanisms provide an element of coverage before the qualifying period is satisfied, for example through the NHS travel costs scheme or other social security benefits.<sup>129</sup>

It also argued that most people would not have to wait six months before receiving payments because, as now, some or all of the qualifying period would have been satisfied before they make their claim.<sup>130</sup>

98. Several witnesses expressed concern about the proposed extension to the qualifying period. Sue Royston of Citizens Advice feared the impact of an extension could be “dramatic”, particularly for people with sudden onset conditions, such as cancer, stroke or accidents. These people, she argued, often experience financial difficulties under the current three-month qualifying period and Citizens Advice was “appalled” by the prospect of an extension to six months.<sup>131</sup> She accepted that PIP should be targeted at those with long-term disabilities or illnesses but suggested that, if a twelve-month Required Period Condition was deemed necessary to meet the definition of long-term disability, the Prospective Test should be extended to nine months with the Qualifying Period left at three months.<sup>132</sup>

99. Eugene Grant of Scope felt that the extension of the qualifying period was a “regressive move”. Geoff Fimister said that RNIB was “strongly opposed” to the possibility of people having to wait six months for support. His view was that the Government’s argument that extending the qualifying period was intended to bring the definition of long-term disability in line with that in the Equality Act was “a bit of an *ex post facto* rationalisation” for a financial saving. Witnesses agreed that a 12-month RPC made up of three months qualifying period plus nine months prospective test was preferable to six months plus six months. However, Paul Farmer of Mind argued that it was important for people experiencing sudden onset conditions to get help “as quickly as reasonably possible”.<sup>133</sup> Geoff Fimister’s view was there was a case for people with these conditions to be able to access support immediately. Paul Farmer agreed that this ought to be the case where there was sufficient medical evidence to indicate a long term impact.<sup>134</sup>

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129 Department for Work and Pensions, *Personal Independence Payment—Policy briefing note: Required period condition*, May 2011, para 10.

130 *Ibid*, para 11.

131 Q 60

132 Q 63

133 Qq 140–142

134 Q 145

100. The Minister emphasised that PIP was intended to support people with long-term conditions. The Government had consulted widely and she felt there was “general agreement” that it should support people whose disabilities would last 12 months or longer. Her view was that it was often difficult to ascertain early on whether a sudden onset condition, such as stroke, would have a long-term impact. She accepted that people with sudden onset conditions could find it “very difficult financially” but, in the short-term, people on low incomes would be supported by means-tested benefits. She also emphasised that the DLA Special Rules allowing immediate support to be given to those with terminal illnesses would be maintained under PIP.<sup>135</sup>

101. On 16 January 2012, we became aware that the Government intended to support an amendment tabled by Baroness Thomas of Winchester at House of Lords Report Stage of the Welfare Reform Bill, amending the PIP qualifying period to three months and the prospective test to nine months. The amendment was agreed in the House of Lords on 17 January 2012.<sup>136</sup>

**102. We welcome the Government’s decision to support a three-month qualifying period for PIP rather than extend it to six months. However, there is evidence of significant financial hardship caused during the current three-month DLA qualifying period, particularly for those with sudden onset conditions such as the loss of limbs after a car accident. We see no reason why claimants with sudden onset conditions, which medical evidence can show to be likely to last at least 12 months, should not receive support immediately. We recommend that DWP implements a facility for early eligibility which could operate in the same way as that for terminal illnesses.**

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135 Qq 212–213

136 HL Deb, 17 January 2012, col 562.

## 5 The draft PIP eligibility criteria

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103. DWP worked with an advisory group of specialists in disability, health and social care to design the proposed new eligibility criteria for PIP. The aim of the criteria is to enable “accurate, objective, consistent and transparent consideration” of individuals’ eligibility.<sup>137</sup> The first draft was published in May 2011. An informal consultation on the criteria ran until August 2011. Alongside the consultation, DWP also contracted Atos Healthcare and G4S Medical Services to conduct trial PIP face-to-face assessments, using the draft criteria, with volunteers who were current or previous working-age DLA recipients. Following the completion of the trial, DWP published a second draft of the criteria in November 2011, inviting further comments from disabled people and their organisations. A further impact assessment was published on 16 January and a formal consultation on the second draft of the criteria was launched.<sup>138</sup> This chapter considers the development of the PIP criteria and the views on them put forward by disabled people and their representative organisations.

### The first draft

104. The PIP assessment will assess claimants’ ability to complete a series of activities that are “key to everyday life”. The level of ability in these activities will be used as a proxy for eligibility for each component of PIP and the rate to which claimants will be entitled—standard or enhanced. The initial list of activities and an “indicative weighting”—whether they would attract a low, medium or high score in the assessment—were published in May 2011:

#### Daily Living component

1. Planning and buying food and drink – medium scoring;
2. Preparing and cooking food – medium scoring;
3. Taking nutrition – medium scoring;
4. Managing medication and monitoring health conditions – low scoring;
5. Managing prescribed therapies other than medication – low scoring;
6. Washing, bathing and grooming – medium scoring;
7. Managing toilet needs or incontinence- medium scoring;
8. Dressing and undressing – medium scoring;
9. Communicating with others – high scoring;

#### Mobility Component

10. Planning and following a journey – high scoring; and
11. Getting around – high scoring.

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<sup>137</sup> Department for Work and Pensions, *Personal Independence Payment: initial draft of assessment criteria: A technical note to support the initial draft of the assessment regulations*, May 2011. Members of the advisory group are: Anne Byrne, College of Occupational Therapists; Itai Chikomo, Community psychiatric nurse/Deputy Manager, attending as an independent member; John Chisholm, Royal College of General Practitioners; Hugh Constant, Social Care Institute for Excellence; Judith Holt, Occupational Therapist, attending as an independent member; Andy Rickell, Equality 2025; Marije Davidson, RADAR; Tom Sensky, Consultant psychiatrist, attending as an independent member; Jenny Storer, Health visitor, attending as an independent member; and Annette Swinkels, Physiotherapist and researcher, attending as an independent member.

<sup>138</sup> Department for Work and Pensions, *Personal Independence Payment: assessment thresholds and consultation*, January 2012.

105. DWP has stated that the activities were chosen to retain the same strong focus on care and mobility as in DLA as these are still considered to be the best proxies. However, they are designed to provide “a more holistic assessment of the impact of a health condition or impairment on an individual’s ability to participate” than under DLA. The criteria also aim to take account of a wider range of impairments than is the case with DLA, including “sensory impairments, developmental disorders, learning disabilities, cognitive impairments and mental health conditions.” DWP’s intention is that the PIP criteria take a less medical approach: “developing criteria which are not based on the type of impairment individuals have but how these affect their everyday lives”.<sup>139</sup>

### **Trial assessments**

106. The draft criteria were tested in trial face-to-face assessments of 937 volunteers in summer 2011. Some 838 of the trial assessments were carried out by G4S Medical Services and 99 by Atos Healthcare. They were conducted by health professionals who produced a written report following each assessment. The health professionals were “experienced” and had a “strong knowledge of a wide range of health conditions and impairments”. They also underwent specific training in preparation for the trial.<sup>140</sup>

### **Criticisms by disability organisations**

107. There are two widely-used models for understanding disability: the “social model” and the “medical model”. Under the social model disability is understood as deriving from barriers placed on people with impairments by society. These barriers include, for example, environmental and practical barriers such as accessibility, where the physical environment has not been designed with the needs of disabled people in mind. Other barriers can include discriminatory attitudes and institutional practices. The social model understands that it is these barriers to participation that have the disabling effects on the individual rather than the individual’s impairments themselves. The social model is able to encompass physical, mental, sensory, cognitive and intellectual impairments. In contrast, a medical model understanding of disability considers that people’s impairments have the disabling effect. It is generally accepted that the medical model is less able to encompass the full range of impairments and is more likely to focus on physical conditions. The Office for Disability Issues, the public body whose role is to promote disability equality across Government departments, fully endorses the social model and considers the medical model to be outdated.<sup>141</sup>

108. A key concern of disability organisations was that the first draft PIP criteria were overly medical and did not pay due regard to the social model of disability. Scope drew attention to the Minister’s assurance, made before the publication of the draft criteria, that the Government was “absolutely committed to a social model” for DLA reform.<sup>142</sup> The

<sup>139</sup> Department for Work and Pensions, *Personal Independence Payment: initial draft of assessment criteria. A technical note to support the initial draft of the assessment regulations*, May 2011.

<sup>140</sup> Department for Work and Pensions, *Personal Independence Payment: second draft of assessment criteria: An explanatory note to support the second draft of the assessment regulations*, November 2011, para 5.3.

<sup>141</sup> See <http://odi.dwp.gov.uk/about-the-odi/the-social-model.php>

<sup>142</sup> HC Deb, 30 November 2010, col 220WH.

Minister reiterated this assurance to us, and told us the assessment would be about asking claimants, “What are the barriers to your living an independent life?”<sup>143</sup>

109. Scope argued that severity of medical condition or impairment was not, on its own, a good indicator of additional disability-related costs. According to research carried out by Demos, social, practical and environmental barriers such as lack of access to public transport, unsuitable housing and lack of family or friend support networks are some of the most important drivers of disability-related costs.<sup>144</sup> This point was highlighted by a man who attended our public meeting in Neath Port Talbot. He was a wheelchair user who was fit enough to have recently completed a half-marathon. However, he faced the same barriers to using public transport, for example railway stations which are not fully wheelchair accessible, as less physically able wheelchair users. As a result he incurred the same extra costs using taxis. Eugene Grant of Scope was concerned that the draft criteria as set out indicated an “overarching principle” of defining ability rather than assessing barriers. He argued this would only give part of the picture, allowing assessors to only partly establish the barriers people faced.<sup>145</sup>

110. Scope, with the support of a range of disability organisations, welfare advice groups and charities, has put forward an alternative PIP assessment. The alternative assessment adopts an approach that Scope says would take greater account of the social model of disability by “accounting for the social, practical and environmental barriers and the disability costs that come with these”.<sup>146</sup>

111. Dr James Bolton, DWP Deputy Chief Medical Adviser, argued that, although the assessment as drafted was “not a fully social model”, it was “not a medical model at all” as impairments would not be considered in a purely medical way.<sup>147</sup> The DWP Minister Lord Freud has also responded to criticism that the assessment was based on the medical model of disability. He emphasised that the assessment would not merely assess level of impairment but would assess the impacts a range of biological, psychological and social factors have on claimants’ ability to complete a range of activities vital for participation in everyday life. He referred to this as a “bio-psycho-social model”. He emphasised that it would not be administratively feasible to take account of every barrier or every extra cost a disabled person might face; an assessment that attempted to do so would be “long, intrusive and costly”.<sup>148</sup>

112. However, a recent report on the Welfare Reform Bill by our colleagues on the Joint Committee on Human Rights concluded that an approach that took better account of the social, practical and environmental barriers disabled people face would be less likely to lead

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143 Q 217

144 Demos, *Counting the Cost*, December 2010.

145 Q 157

146 Scope, *The Future of PIP: a social model-based approach*, October 2011, p 4.

147 Q 239

148 HL Deb, 14 November 2011, col 198GC.

to incompatibilities with the UK's obligations under the UN Convention on the Rights of Persons with Disabilities.<sup>149</sup>

### ***Focussing on those with “greatest needs”***

113. There was consensus amongst disability representative organisations that “greatest need” was not an accurate proxy for extra costs. Blind people’s organisations argued that a focus on need could run counter to the intention of the benefit, the aim of which is to help towards the extra costs of disability.<sup>150</sup>

114. Claudia Wood of Demos thought that the Government’s approach risked conflating the definition of “greatest need” with severity of impairment and that this would be an inefficient method of measuring extra costs:

If we reserve it just for people with the greatest needs, there are going to be people there who have complex conditions who may have very well adapted homes, a partner who supports them and accessible transport, and do not necessarily have huge living costs. So there is a mismatch on the targeting there, and that could be inefficient for the Government. It is not just about people with low needs and high costs, but also about people with high needs and low costs getting more than they necessarily need.<sup>151</sup>

### ***Approach to fluctuating conditions***

115. In our inquiry into the reassessment of Incapacity Benefits claimants using the Work Capability Assessment (WCA), we highlighted the findings of Professor Malcolm Harrington’s independent review of the WCA for DWP.<sup>152</sup> He identified that the WCA faced difficulties in assessing variable and fluctuating conditions and pointed to the widely held view that the WCA provided only a “snapshot” of health conditions on the day of the assessment as it was not sufficiently flexible to take a longer term view. The WCA also failed properly to assess claimants’ ability to repeat tasks and to take account of the impacts of pain and fatigue.

116. After considering the issues in more detail in his second annual independent review, Professor Harrington concluded that the WCA descriptors needed to be more multi-dimensional, in particular taking into account frequency, severity and duration of symptoms. He also recommended that the criteria were clearly worded to encompass claimants’ ability to complete activities “reliably, repeatedly and safely” and, where appropriate, “within a reasonable amount of time”.<sup>153</sup> It is clear from Professor Harrington’s second report that there remains considerable difficulty in agreeing

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149 Joint Committee on Human Rights, Twenty-first Report of Session 2010–12, *Legislative Scrutiny: Welfare Reform Bill*, HL Paper 233/HC 1704, para 1.75.

150 Ev 72

151 Q 49

152 Work and Pensions Committee, Sixth Report of Session 2010-12, *The role of incapacity benefit reassessment in helping claimants into employment*, HC 1015, paras 101–105.

153 Professor Malcolm Harrington, *An Independent Review of the Work Capability Assessment – year two*, November 2011, para 24.

descriptors and the assessment process in relation to fluctuating conditions (and also for mental, cognitive and learning disability descriptors) in relation to the WCA. This illustrates the need to give the fullest possible consideration to these issues in designing the PIP assessment.

117. DWP has stated that it is “essential” that the PIP assessment deals effectively with variable and fluctuating conditions. It originally set out its proposed approach as follows:

[...] decisions should be made having considered the impact of impairments over a twelve month period and [...] should consider impacts that occur for the majority of the time in that period. If one of the assessment criteria cannot be completed in the way described within the descriptors for more than six months, aggregated over the twelve month period, then it should be viewed as not being able to be completed at all.<sup>154</sup>

118. Professor Sainsbury acknowledged that effectively assessing fluctuating conditions was “very difficult” but he felt the above approach would be “a nightmare for the assessors and for claimants”.<sup>155</sup> Mental health organisations agreed that this approach risked failing to recognise the true nature of fluctuating conditions; they argued that it would be perverse for claimants with moderate mental health conditions that were present more than 50% of the time to be assessed as eligible if claimants with severe mental health conditions, such as acute psychoses, present less than 50% of the time were not entitled to the benefit. This approach was unlikely to reflect either need or additional costs accurately.<sup>156</sup>

### ***Taking account of aids and appliances***

119. Disabled people often use aids and appliances to help them overcome barriers to participation. Aids and appliances include, but are not limited to: walking aids such as sticks; wheelchairs; hearing aids; and computer equipment and software. DWP’s view is that the PIP assessment should take some account of the use of aids and appliances to establish the correct level of benefit people are entitled to.<sup>157</sup>

120. Several witnesses argued that taking account of successful use of aids and appliances in assessing eligibility for PIP could act as a disincentive to people actually using them.<sup>158</sup> One individual who used a computer, in part financed through his DLA, to help him to communicate felt that it would be “ridiculous and discriminatory” if his successful use of the computer to overcome his communication barrier counted against him in the PIP assessment.<sup>159</sup>

121. The Disability Benefits Consortium emphasised the importance of taking account only of aids and appliances that are *actually* used rather than those that could potentially be used. It also argued that people using aids and appliances should still be able to qualify for

<sup>154</sup> Ev 103

<sup>155</sup> Q 70

<sup>156</sup> Ev 55–56

<sup>157</sup> Ev 103

<sup>158</sup> See, for example, Martin Wilsher, Ev w4 and Geoff Fimister, Q 161

<sup>159</sup> Martin Wilsher, Ev w4



the benefit, to reflect the additional costs they often incur. These costs could include “buying, charging and maintaining an electric wheelchair, fuelling and insuring an adapted vehicle or even feeding an assistance dog”. It argued that such an approach would be necessary to maintain the benefit’s focus on meeting additional costs.<sup>160</sup>

122. DWP has accepted that aids and appliances do not “remove an individual’s impairment” and might, in any case, incur ongoing costs to the people who use them. It therefore acknowledged that its approach needed to be undertaken “sensitively and proportionately”. DWP gave an assurance that the assessment would award points to people who successfully use aids and appliances and stated: “It will be entirely possible for individuals who use aids and appliances to receive sufficient point scores to qualify for the benefit, as long as they meet the criteria.”<sup>161</sup>

## The second draft

123. Following the summer 2011 trial assessments, DWP issued revised draft criteria in November 2011. It stated that, although “it has not been possible to reflect all comments”, the revised criteria “build heavily on the views of disabled people and their organisations”. The key changes that have been made since the first draft are:

- The criteria now take account of where the presence of another person is needed by referring to “**supervision**” where this is required to enable an individual to carry out an activity safely.
- Descriptors are designed to establish the impacts of conditions which are present “the majority of the time” i.e. on the majority of days. However, in order to “accurately capture” the impact of **fluctuating conditions**, “where two or more descriptors in an activity apply on less than 50 per cent of days individually but reach this threshold when combined, the descriptor which applies for the greatest proportion of time will apply”.
- In order to “ensure a **broader assessment of ability** to make everyday decisions” the previous “Planning and buying food and drink” activity has been replaced with the new “Making financial decisions” activity.
- The previous “Communicating with others” activity has been split into two new activities: “**Communicating**” and “**Engaging socially**”. The aim is to capture both ability to communicate *and* ability to interact with others in “an appropriate manner, understand body language and establish relationships”.
- **A number of definitions have been broadened.** A “simple meal” is now one defined as made from fresh ingredients — not frozen. Medication and therapy may now be “recommended” rather than only “prescribed”. “Communication support” can be from any person experienced in communicating with the individual, not just from someone who is trained to provide that support.

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<sup>160</sup> Ev 65

<sup>161</sup> Ev 103

- DWP states that it recognises that **aids and appliances** “do not necessarily remove barriers and may attract costs”. Therefore descriptors that refer to use of aids and appliances “normally attract a score”.

The descriptors relating to mobility still concentrate on the ability to move prescribed distances and on the need for supervision. The opportunity has not been taken to consider more fully the difficulties encountered by users of public transport and the differential impact of location (for example, where the routes to shops, workplaces or to reach public transport are hilly or stepped). The explanatory notes accompanying the second draft included suggested point scores for each of the activity descriptors. However, the points thresholds for eligibility were not published until 16 January 2012.<sup>162</sup>

124. The DWP Chief Medical Adviser told us that a number of people who had taken part in the trial had fluctuating conditions. DWP had learned from the trial and its approach to such conditions had changed slightly. The assessment would now assess a condition’s impact on ability in “the majority of the day” rather than “the majority of the time”. He felt that this approach would be easier to understand and apply. The Minister told us that the assessment would consider whether activities could be completed “safely, reliably, repeatedly and in a timely manner”. If a claimant could not repeat a task due to pain or fatigue they would be considered unable to complete the task at all. Dr Bolton said the approach to fluctuating conditions would be considered further during a formal consultation in 2012 and this has now been announced by DWP (see below).<sup>163</sup>

125. Some of the changes outlined above have been welcomed by disability representative organisations. Geoff Fimister of RNIB told us that they signified that DWP officials had been listening to their concerns.<sup>164</sup> Amanda Batten of the National Autistic Society felt the revised criteria were a significant improvement on the first draft and “perhaps on the DLA form”. She thought the descriptors on social interaction and communication better reflected the difficulties faced by people with autism, for example. However, witnesses also felt that it would be impossible for 12 activity descriptors to capture the impacts of complex conditions; Amanda Batten and Paul Farmer of Mind felt that there needed to be some way for claimants to describe their own conditions, as was the case with DLA.<sup>165</sup>

126. Scope believed the second draft of the criteria was an improvement on the first but felt the changes made amounted only to “tweaks”. It was disappointed that its recommendation to incorporate a range of social, practical and environmental factors had not been implemented. Its view was that the assessment remained a medical model test and therefore the risk remained that the assessment would not be an effective measure of disability-related costs. It highlighted what it saw as inconsistencies in the language used to describe the purpose of the benefit; DWP had referred to targeting “those with the greatest needs”, “needs arising from a health condition or impairment”, “those most affected by their health condition or impairment” and “those who face the greatest barriers to

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162 Department for Work and Pensions, *Personal Independence Payment: assessment thresholds and consultation*, January 2012.

163 Q 240

164 Q 157

165 Q 157

participating in everyday life”. Scope urged DWP to make it clear that PIP is intended to support those facing the greatest barriers to participation in society. It was also concerned that DWP had included, at this stage of the design process, suggested points scores for the descriptors in each assessment activity. Its view was that this was an attempt by the Government to move the debate on before proper consideration of the “underlying principles” of the activity descriptors themselves.<sup>166</sup>

## Plans for further development

127. DWP has stressed that the development of the PIP criteria will be an iterative process. On 16 January 2012 it launched a 15-week consultation on the second draft of the criteria which will run until 30 April 2012. Its intention was that “final draft regulations” would be laid before Parliament later in 2012.<sup>167</sup>

**128. We welcome the changes made to the first draft of the PIP assessment criteria. We believe they demonstrate that the Government has listened to concerns expressed by disabled people and their representatives. DWP deserves credit for the way it has involved them in the “co-production” approach it has adopted to the development of the PIP criteria.**

**129. We fully support the Government’s intention to ensure PIP is fairer, more consistent and takes a more holistic, “social model” account of the impacts of disability. One of the Government’s declared aims for PIP is to improve on the assessment used for DLA. So far, mobility descriptors still concentrate heavily on ability to move a fixed distance and do not include barriers to accessing public transport, or the difficulties of some locations for individuals where routes to shops, public transport etc are particularly hilly or stepped. The PIP assessment criteria, as drafted, tend towards the medical model of disability. We recommend that, as part of the consultation with disability representative organisations on the second draft of the criteria now under way, the Government considers how activity descriptors could take account of the impact of such factors as housing, access to public transport and hilly locations.**

**130. We recommend that the Government undertakes a further trial of the assessment criteria once they have been revised following the consultation and that the results of the trial are published before the criteria are laid down in Regulations under the Welfare Reform Bill.**

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<sup>166</sup> Scope briefing on the second draft PIP criteria, available at [www.epolitix.com](http://www.epolitix.com)

<sup>167</sup> Department for Work and Pensions, *Personal Independence Payment: assessment thresholds and consultation*, January 2012, para 1.8.

## 6 Implementation of PIP

131. This chapter discusses the assessment model for PIP in more detail. As described in the previous chapter, the assessment will award points to claimants on the basis of their ability to complete a range of activities. The assessment model is similar to that used in the Work Capability Assessment (WCA) for Employment and Support Allowance (ESA). We consider the lessons that need to be learnt from the WCA experience. We assess DWP's view that "most claimants" will require a face-to-face-assessment. We look at DWP's plans to deliver the assessment through contracts with private companies. We also consider DWP's plans for implementation of the new benefit and what needs to happen before implementation begins.

### Similarities with the WCA

132. DWP's proposed assessment will be similar to the WCA in that claimants will "score" points against activity descriptors and their cumulative score will be used to help determine eligibility and level of award. A total of 8 points in activities 1 to 9 will be required to qualify for the standard rate of the daily living component; 12 points will be required for the enhanced rate. The same thresholds will apply for the mobility component, assessed against activities 10 and 11.<sup>168</sup>

*As an example of how the PIP assessment will be structured, set out below are the descriptors in the "moving around" activity along with the proposed number of points a claimant will "score" for satisfying each descriptor:*

- **No points** – *If they can move at least 200 metres either –  
Unaided; or  
Using an aid or appliance, other than a wheelchair or a motorised device*
- **4 points** – *If they can move at least 50 metres but not more than 200 metres either –  
Unaided; or  
Using an aid or appliance, other than a wheelchair or a motorised device*
- **8 points** – *If they can move up to 50 metres unaided but no further*
- **10 points** – *If they cannot move up to 50 metres without using an aid or appliance, other than a wheelchair or a motorised device*
- **12 points** – *If they cannot move up to 50 metres without using a wheelchair propelled by the individual*

<sup>168</sup> Department for Work and Pensions, *Personal Independence Payment: assessment thresholds and consultation*, January 2012, para 1.4.

- **15 points** – *If they cannot move up to 50 metres without using a wheelchair propelled by another person or a motorised device*
- **15 points** – *If they cannot either –  
Move around at all; or  
Transfer unaided from one seated position to another adjacent seated position.*<sup>169</sup>

133. DWP is still in the process of developing the delivery model for the PIP assessment but it outlined some of its intentions:

- Claimants will be allowed to bring another person with them to the assessment (e.g. family member, friend or advocate)
- The assessments will take place on official premises or at a claimant's home where necessary
- The outcome of the assessment will be advice to the Department to support decisions on benefit award and duration
- Final decisions on entitlement will be taken by Decision Makers (DMs) within DWP
- DMs will be able to consider all evidence provided as part of the claim before making a decision
- There will be an independent review of the operation of the PIP assessment, the report of which will be laid before Parliament.<sup>170</sup>

This seems remarkably similar to the WCA model.

134. As we have noted, Professor Malcolm Harrington's first independent review of the WCA found some significant failings: it could be impersonal and inflexible; it lacked transparency; and poor decisions were being made due to a lack of communication between those involved in the process. He made several recommendations aimed at: improving DWP decision-making; making the process more compassionate; improving the transparency of the assessment; and taking account of particular difficulties in assessing certain conditions, in particular mental health and other fluctuating conditions.<sup>171</sup>

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<sup>169</sup> Department for Work and Pensions, *Personal Independence Payment: second draft of assessment criteria: An explanatory note to support the second draft of the assessment regulations*, November 2011, pp 61–62.

<sup>170</sup> Ev 105. DWP originally specified that the independent review would take place "within three years" but this was amended at Report Stage of the Welfare Reform Bill in the Lords to two biennial reviews; the first within two years and then within four years of implementation (see paragraph 164 below).

<sup>171</sup> Professor Malcolm Harrington, *An Independent Review of the Work Capability Assessment*, November 2010.

135. The Government accepted the Harrington recommendations and has made progress in implementing them.<sup>172</sup> In our report on the IB reassessment, we welcomed improvements made to the WCA process following the first Harrington Review but also noted that the WCA, as introduced in 2008, was flawed and that claimants had received a service from Atos Healthcare, the private company contracted to deliver the WCA, which fell below acceptable standards.<sup>173</sup>

136. Professor Harrington recently published his second annual independent review of the WCA, making recommendations aimed at further improving the process. He found that communication between those involved in the decision-making process (Jobcentre Plus Personal Advisers and Decision Makers, Atos Assessors and the First-tier Tribunal) still needed to improve. He also recommended regular audit of Decision-Makers' performance and regular publication of data to "ensure consistency and that standards are not allowed to slip".<sup>174</sup>

137. A number of witnesses urged DWP to heed the lessons learned from the Harrington reviews. For example, Citizens Advice Scotland stated:

CAS is deeply concerned that the introduction of a medical assessment for DLA will be similar to that used for Employment and Support Allowance (ESA) claims. The consultation does not acknowledge the recently published review of the work capability assessment, which raises serious concerns over how the system functions and clearly highlights how ESA claimants are not being treated with dignity and respect. The Harrington Review recommendations for changes to the WCA are enthusiastically accepted in an ESA context. Lessons need to be learnt from this review before any PIP assessment is introduced.<sup>175</sup>

The Disability Benefits Consortium claimed that any "rush" to implement the PIP assessment risked "history being repeated".<sup>176</sup>

138. Dr Bolton told us that DWP had learned a great deal from the Harrington reviews and that this was "central" to the development of the PIP assessment. The Minister emphasised that the purpose of the two assessments was fundamentally different but there would be some common learning and that DWP officials working on each assessment could share their experience.<sup>177</sup> The PIP assessment was intended to be a "conversation" between claimant and assessor, avoiding the mechanistic approach originally adopted in the WCA.<sup>178</sup>

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172 Department for Work and Pensions, *Government's response to Professor Malcolm Harrington's Independent Review of the Work Capability Assessment*, November 2010.

173 Work and Pensions Committee, Sixth Report of Session 2010-12, *The role of incapacity benefit reassessment in helping claimants into employment*, HC 1015, para 92.

174 Professor Malcolm Harrington, *An Independent Review of the Work Capability Assessment – year two*, November 2011, p 8.

175 Ev w42

176 Ev 65

177 Qq 216–217

178 Q 235

139. We were encouraged by the language used by the Minister in describing the PIP assessment as a “conversation” between claimant and assessor. It is vital that the PIP assessment does not take the same mechanistic approach, based on an inflexible computer system, originally adopted for the WCA in 2008. We believe that healthcare professionals administering the assessments should take an empathetic approach that allows claimants to describe the impacts of their disabilities or health conditions on their everyday lives. We recommend that DWP sets out this principle in the published guidance for healthcare professionals on the assessment process. This approach will have implications for the time allowed for face-to-face assessments, which in turn must be reflected in the contract arrangements with the third party providers of the assessments. We would seek assurances from the Government that this will be taken into account in the contracting process.

### **Claimant experience in the trial**

140. The trial of the PIP assessment discussed in the previous chapter focused only on the reliability and validity of the criteria. It was not designed to test the assessment process or delivery. Nevertheless, Dr Bolton told us that DWP had received excellent feedback from volunteers about their experience.<sup>179</sup> Some 198 of the 838 volunteers whose trial assessment was conducted by G4S Medical Services returned a customer satisfaction survey. Of those who responded, 92% commented positively. Atos Healthcare carried out 99 trial assessments but did not conduct a similar survey and was not required by DWP to do so.

141. However, disability organisations had concerns about the trial. Sense highlighted several problems experienced by deaf-blind people who took part, including: information for participants sent out in inaccessible formats; overlooking individuals’ preferred method of communication; failure to book the correct communication support for people attending the trial assessment; and assessors’ lack of awareness of deaf-blindness.<sup>180</sup>

142. The Disability Benefits Consortium told us that it had offered to take part in trials of the assessment but DWP had turned down its offer. It was also not permitted to witness the G4S/Atos trial, which it said had not reassured disabled people that “the new assessment is being developed in the most inclusive or transparent manner”.<sup>181</sup>

### **Ending automatic entitlement**

143. People with severe mental impairment, deaf-blindness, severe visual impairment, double amputees and those undergoing haemodialysis qualify automatically for DLA. The Government does not propose to allow automatic entitlement for PIP on the basis of any specific condition or impairment. It believes that this approach will allow for more personalised support based on individual circumstances. It “does not think it right” that people should be “labelled” purely on the basis of the type of impairment they have.<sup>182</sup>

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179 Q 215

180 Sense, *Personal Independence Payment & deafblind people: Learning the lessons from testing the first draft assessment criteria in Summer 2011*, November 2011.

181 Ev 65

182 Ev 99

144. Mencap sympathised with an individualised approach but also urged DWP to adopt a “pragmatic” approach.<sup>183</sup> Other witnesses appealed for particular degenerative conditions, such as muscular dystrophy and multiple sclerosis, to confer automatic eligibility or exemption from regular reviews.<sup>184</sup> Disability Alliance and RNIB both highlighted deaf-blindness as a condition unlikely to change and likely to incur ongoing extra costs over a lifetime. Geoff Fimister’s view was that it would be “totally pointless” to subject deaf-blind people to the new assessment.<sup>185</sup>

145. Sue Royston of Citizens Advice acknowledged the arguments both in favour and against automatic entitlement. Her view was that there should be “at least a minimum level of automatic entitlement” for some groups. She felt that, even if there was not automatic entitlement for particular conditions, it was clear that some people ought not to be required to undergo a face-to-face assessment. She gave the example of someone with cerebral palsy who was a wheelchair user and had no control of their bodily functions.<sup>186</sup>

### ***Do most individuals need a face-to-face assessment?***

146. DWP stated that “an important part of the Personal Independence Payment assessment process for most individuals should be a face-to-face consultation with the assessor.”<sup>187</sup> However, there will be some exceptions:

For example, where there is already sufficient evidence available to strongly support a decision on benefit entitlement, requiring individuals to attend a consultation may be unnecessary. In these circumstances, making an assessment based on paper evidence might be more appropriate. The Government believes, however, that such decisions on whether a face-to-face consultation is necessary, should be made on a case-by-case basis, considering the available evidence, not on the basis of the health condition or impairment individuals have.<sup>188</sup>

147. Some witnesses questioned the assumption that “most people” would require face-to-face assessment. Amanda Batten of NAS felt that this would be “impractical and unnecessary” for some people, although she could not estimate the proportion. At our public meeting in Neath Port Talbot, a parent with an autistic son aged 22 pointed out that his condition had required assessment over a two-week period by a clinical psychologist. She believed that an hour long PIP assessment by a medical professional with no expertise in autism would have little value in comparison. Her view was that evidence provided by medical experts with a long-term relationship with the claimant was the most reliable resource on which to rely.

148. Experience of the WCA shows that the prospect of a face-to-face assessment causes worry, stress and anxiety even amongst those who meet the criteria and easily qualify for

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183 Ev w17

184 Muscular Dystrophy Campaign, Ev w36; MS Society, Ev w53; Motor Neurone Disease Association, Ev w65

185 Q 149

186 Qq 100–103

187 Ev 99

188 Ev 99



ESA.<sup>189</sup> Geoff Fimister of RNIB believed face-to-face assessments had become “a bit of a fetish” within the current DLA reforms. He argued that the result could be not only unnecessary anxiety for claimants but also a waste of public resources. He also felt overuse of assessments ran counter to the Government’s aim for more streamlined administration of the benefits system.<sup>190</sup>

149. The Minister confirmed that some individuals would not be required to attend a face-to-face assessment where there was already sufficient evidence on which to base a decision. She acknowledged that this would “not be a good use of either that individual’s time or taxpayers’ money.” DLA face-to-face assessments, which are used much less frequently than is proposed for PIP, cost around £14 million in 2010–11.<sup>191</sup> The estimated cost of PIP assessment contracts is estimated to be between £300 and £500 million over seven years.<sup>192</sup>

### **Potential impact on the Tribunals Service**

150. Our Report on the IB reassessment drew attention to the increased number of social security appeals heard by the Tribunals Service. Our colleagues on the Justice Select Committee had found that appeals had increased from 242,800 in 2008–09 to an estimated 436,000 in 2011–12, mainly due to the introduction of ESA. They also reported that the cost to DWP of social security appeals heard by the Tribunals Service had increased significantly in recent years from £1.3 million in 2008–09 to £9 million in 2009–10 and an estimated £21.1 million in 2010–11.<sup>193</sup>

151. *The Times* recently reported that the Government had recruited 84 new judges to the Social Entitlement Chamber of the Tribunals Service in order to deal with the “bottleneck” of cases arising from the Government’s welfare reforms. It reported that appeals in 2010–11 were up 23% on the preceding year and 72% on 2008–09 and that this “unprecedented workload” was a major contributory factor in increased running costs of the Tribunal Service.<sup>194</sup>

**152. We agree with the Government that more reassessment of claims is necessary than has been the case with DLA. However, too frequent reassessment risks wasting public money and causing stress and anxiety to disabled people. The personal interview should play a part in assessing many PIP claimants. Face-to-face assessment should include the option for home visits where this is agreed to be appropriate. These steps may help to avoid cases going to appeal, with the accompanying costs and delays in resolving claims.**

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189 Work and Pension Committee, Sixth Report of Session 2010–12, *The role of incapacity benefit reassessment in helping claimants into employment*, HC 1015, para 24.

190 Q 126

191 HC Deb, 10 January 2011, col 212W.

192 Supplement to the Official Journal of the European Union, *Health and Disability Assessment Services Framework*, January 2012, p 4.

193 Work and Pensions Committee, Sixth Report of Session 2010–12, *The role of incapacity benefit reassessment in helping claimants into employment*, HC 1015, para. 140.

194 “Benefits appeals send costs soaring”, *The Times*, 28 November 2011

153. We consider that there is a case for automatic entitlement for some claims. The WCA is being carried out annually in a number of cases, which can cause considerable stress for some people. The case for annual assessment is less compelling for PIP than for WCA which is judging people's ability to re-enter employment. We recommend that there should be flexibility in the frequency of PIP reassessment and that the Government monitors the impact of this.

154. Once the initial assessments for PIP have been completed in the first geographical area, we recommend that the Government looks again at the value of face-to-face assessments for PIP claims where the condition is severe and unlikely to change. The Government should reconsider whether, in many cases, reliance on medical evidence gathered over a period of time and based on detailed knowledge of the claimant would have more validity than the snapshot of a claimant's condition and its impacts on their ability to participate in society which can be gained in a relatively short interview with a healthcare professional who is not an expert in their condition.

## Contracting

155. As noted, the potential value of PIP assessment contracts is estimated to be between £300 and £500 million over seven years.<sup>195</sup> In our inquiry into the migration of claimants from IB to ESA, we recommended that DWP consider contracting more than one company to undertake benefits assessments when the current Medical Services contract with Atos Healthcare expires in 2015. We believed this approach would act as a lever to drive up standards through competition between suppliers. We also concluded that there were insufficient levers within DWP's contract with Atos Healthcare to ensure it produces accurate assessment reports on a consistent basis. We recommended DWP review the performance indicators in future contracts with a view to linking payment to a quality standard which ensured that assessment reports are "right first time".<sup>196</sup>

156. DWP's original intention was that the PIP assessment would be delivered separately from other benefits assessments through "a third party" contracted to the Department. Simon Dawson of DWP told us that the procurement process for the PIP assessment contract had already commenced. A Prior Information Notice (PIN) for potential suppliers of a separate PIP assessment was published in the Official Journal of the European Union in September 2011.<sup>197</sup> Mr Dawson reported a "considerable amount of interest" from a range of suppliers.<sup>198</sup>

157. The initial PIN has since been superseded by a PIN for potential suppliers to a new Health and Disability Services Framework. The competition for the Framework will identify "organisations (including consortia) that have the capacity and expertise to deliver" services in support of a range of functions, including decisions on social security

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195 Supplement to the Official Journal of the European Union, *Health and Disability Assessment Services Framework*, January 2012, p 4.

196 Work and Pensions Committee, Sixth Report of Session 2010-12, *The role of incapacity benefits reassessment in helping claimants into employment*, HC 1015, para 93.

197 Supplement to the Official Journal of the European Union, *Personal Independence Payment (PIP) Assessment Service (Collaborative)*, September 2011.

198 Q 226

benefits. The PIN states that the framework agreement will be divided into lots, meaning there will be more than one potential supplier for each region or area. The number of lots and the number of suppliers allocated to each lot is yet to be decided.<sup>199</sup>

158. The model for the framework appears to be similar to the framework for the provision of Employment Related Support Services (ERSS), used for the delivery of the Work Programme. The ERSS is essentially an umbrella agreement between DWP and potential suppliers who have in effect been pre-approved to bid for specific Work Programme contracts in specific lots. Our Report on the contracting arrangements for the Work Programme welcomed the establishment of the ERSS as a way of encouraging innovation and competition amongst different providers. We also welcomed the fact that it allows DWP to replace poorly performing providers with others from a pre-approved list.<sup>200</sup> We understand the competition for the PIP assessment will be the first to draw on suppliers under the new Health and Disability Services Framework.

**159. We recommend that DWP contracts with private companies for delivery of the PIP assessment directly link the payment of public funds to the production of reliable assessment reports that are “right first time”. We welcome the framework approach which has now been adopted for benefit assessment contracts and request further details about how it will operate, in response to this Report.**

**160. Experience with the Work Capability Assessment has demonstrated the need for large Government contracts with private suppliers which involve sensitive health and disability assessments to be properly monitored. We therefore request further information on how the Government plans to oversee and regulate the contracts for the PIP assessments. We would also like to see the contractors’ communication with individuals who are deaf-blind reflecting their communication barriers.**

## Implementation plans

161. HM Treasury’s original announcement of DLA reform included an assumption that PIP would be implemented from 2013 over 3 years, with 25% of current working-age DLA recipients reassessed in 2013–14, 75% of the total by the end of 2014–15 and 100% by the end of 2015–16.<sup>201</sup> DWP’s submission contained no more information on timescales beyond confirming its intention to introduce the benefit for both new claims and existing working-age DLA recipients from 2013.<sup>202</sup> In December the Minister told us DWP would set out further details in the new year and that DWP was likely to consult on how the new benefit would be phased in. She expected implementation to begin with new claims then “build up from there”.<sup>203</sup>

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199 Supplement to the Official Journal of the European Union, *Health and Disability Assessment Services Framework*, January 2012, p 3.

200 Work and Pensions Committee, Fourth Report of Session 2010-12, *Work Programme: providers and contracting arrangements*, HC 718.

201 HM Treasury, *Budget 2010 policy costings*, June 2010, p 36

202 Ev 104

203 Q 228

162. The DWP Minister Lord Freud, speaking in the Lords Report Stage debate on the Welfare Reform Bill on 17 January 2012, confirmed that DWP would move away from a “big-bang” approach to implementation. DWP’s intention was that PIP would be implemented for new claims only from April 2013 and that the number of new claims would be limited to “a few thousand per month for the first few months”. An amendment to the Bill tabled by Baroness Grey-Thompson, calling for a trial period for new and existing claims before full implementation of PIP, was narrowly defeated. However, a Government Amendment to the Bill agreed on 1 February 2012 allows the Government initially to implement new PIP claims in one geographical area.<sup>204</sup>

163. Reassessment of *existing* DLA claims is planned to commence in autumn 2013, beginning with fixed-term claims that were due for renewal or in which the claimant had reported a change in circumstances. DWP also plans to conduct a three-month “pathfinder trial” in autumn 2013 of reassessment of claims which would not, under the existing DLA system, be due for reassessment. Lord Freud expected the pathfinder trial to enable DWP to ensure the processes were working satisfactorily ahead of a full national implementation.

164. Lord Freud also announced revised plans for independent reviews of PIP; there would be two biennial reviews within the first four years of implementation. The first review would report within two years of the relevant Regulations coming into force; the second within four years.<sup>205</sup>

**165. The high number and cost of appeals in the original WCA process highlights the risk in introducing a new benefit assessment without full consultation and thorough testing. The challenge of accurately assessing DLA/PIP claims is arguably greater than incapacity benefit claims. The WCA simply assesses capacity to work. The PIP assessment will need to provide an accurate indication of the impact of complex conditions and combinations of conditions on participation in society in a variety of life contexts. It is therefore essential that DWP allows itself sufficient time to get the assessment right and to be able to convince disabled people and their representatives that this is the case. Implementation timescales should not be driven by artificial deadlines set by HM Treasury before the details of the reform were known.**

**166. We welcome the Minister’s confirmation that DWP does not intend to press ahead with a “big bang” approach to implementation of PIP and his commitment to begin with new claims only from April 2013. We note that the Government plans initially to introduce new PIP claims in one geographical area. The area should be selected on the basis of carefully defined criteria. The period prior to national roll-out should be used to prepare a methodology for monitoring the early lessons to emerge from implementation and to ensure that recommendations for changes can be made quickly, in consultation with interested bodies.**

**167. We welcome the Government’s decision to bring forward the first independent review of the PIP assessment to within two years of the assessment Regulations coming into force and to have a second independent review within four years of that date.**

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204 HC Deb, 1 February 2012, col 951.

205 HL Deb, 17 January 2012, cols 518–532.

168. As has been shown with the WCA/ESA process, reassessment of existing claims is even more complex and challenging than dealing with new claims. We therefore believe that reassessment of existing DLA claimants should only proceed once the Department is confident that the assessment is accurate.

### *Interaction with other assessments*

169. As we have highlighted, the Government plans to reassess around 1.5 million IB claimants for the new ESA benefit by 2014. Many of these claimants will be among the current approximately two million working age DLA recipients. The Disability Benefits Consortium reported that many disabled people already feel “over-assessed”. Its view was that in many cases further “stressful and intrusive” assessments of the type proposed for PIP could cause harmful stress and anxiety and aggravate medical conditions.<sup>206</sup> Neil Coyle of Disability Alliance told us that many disabled people would prefer information to be shared between relevant agencies to establish entitlement for PIP and that the drive to personalise the assessment should be balanced against the potential impacts on health and wellbeing that frequent reassessment can have.<sup>207</sup> Mental health organisations urged the Government to make efforts to use existing medical evidence, for example that provided for WCAs, wherever possible to avoid the need for face-to-face assessments.<sup>208</sup>

**170. The phasing in of the reassessment for Personal Independence Payment should take account of the timing for individuals of the Work Capability Assessment for Employment and Support Allowance. There is likely to be a significant overlap between the two groups of claimants and many disabled people may already have had one or more WCAs by the time the PIP reassessment is introduced. The cumulative impact of frequent reassessment on a vulnerable group of people should not be underestimated.**

### *The Motability Scheme*

171. DLA higher rate mobility component currently acts as a gateway to the Motability Scheme, which is designed to help disabled people to contract hire a specially adapted car, powered wheelchair or scooter. Some 95% of participants in the Motability Scheme use it to contract hire a car for three years, with the costs of tax, insurance, servicing and breakdown covered.<sup>209</sup> It is not yet clear which rate of PIP will confer eligibility for the Motability Scheme.<sup>210</sup> However, a number of witnesses were concerned that the new eligibility criteria for PIP could result in some current DLA higher rate mobility component recipients failing to meet the criteria for the enhanced rate of PIP and therefore losing their eligibility for the Motability Scheme.<sup>211</sup> Although, as we noted in chapter 4, it is not possible to ascertain from which DLA rate combinations the reduction in PIP caseload

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206 Ev 66

207 Q 174

208 Ev 53

209 Ev w138

210 Department for Work and Pensions, *Personal Independence Payment—Policy briefing note: Passporting from Personal Independence Payment*, November 2011.

211 Lisa Egan, Ev w6; Citizens Advice, Ev 60; Carers UK, Ev w21

will come, it does appear likely that a significant number of recipients of higher rate DLA mobility will not meet the criteria for the enhanced rate of PIP mobility component.<sup>212</sup>

**172. We recommend that the Government clarifies, in response to this Report, which rate of PIP mobility component will confer eligibility for the Motability Scheme. It should also clarify whether a three-year lease for a Motability car, signed when the claimant was a recipient of higher rate DLA mobility component, will be terminated if that person is found ineligible for the Motability Scheme under PIP. We believe it is important for the Government to provide certainty on these issues before reassessment of the working-age DLA caseload commences.**

### **Children and young adults**

173. The current proposals do not apply to children under 16 years of age. DWP has said that it will not come forward with proposals for reform of DLA for children until working-age PIP has been implemented and the experience can be used to inform its decisions.<sup>213</sup> A number of witnesses welcomed this approach.<sup>214</sup> The Disability Benefits Consortium reported that DWP had initiated discussion about how best to include children in PIP.<sup>215</sup> Citizens Advice recommended a separate and full consultation before any extension of PIP to children.<sup>216</sup> As we have noted, we are likely to look again at DLA reform once the Government has come forward with its proposals for non-working age claimants.

174. Several witnesses raised the issue of the implications of the introduction of PIP for young adults and those in the transition to adulthood. CLIC Sargent felt that the Government's distinction between non working-age (0–15 years) and working age (16–64 years) risked establishing a system that would not adequately recognise the “unique needs” of young people. It also argued that this approach would run counter to proposals to increase the participation age to 18 and those outlined in the Department for Education's recent Green Paper, which sets out proposals for a single coordinated assessment of disability and special educational needs and the creation of an education, health and care plan for those up to the age of 25.<sup>217</sup> CLIC Sargent argued that young people aged 16 to 18 should be treated as a distinct group from the working-age population and that reforms affecting them should be considered alongside those for children.<sup>218</sup>

175. DWP has stated that its objective in relation to young adults is to ensure “effective transition [...] from DLA to PIP at age 16”. Its view is that 16 is the correct age at which people should be assessed against adult criteria. Its rationale is that young people over the age of 16 will have a choice of whether to remain in education, undertake training or enter employment and therefore applying PIP to 16 to 18 year-olds is “broadly compatible” with

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212 <http://janeyoung.me.uk/2012/01/19/thousands-could-lose-motability-vehicles/>

213 Ev 95

214 For example, Mencap, Ev w18; Muscular Dystrophy Campaign, Ev w39

215 Ev 66

216 Ev 61

217 Department for Education, *Support and aspiration: A new approach to special educational needs and disability*, Cm 8027, March 2011.

218 CLIC Sargent, Ev w73

provisions to raise the participation age. However, DWP is undertaking work with organisations representing disabled young people on specific proposals for delivery of PIP for those aged 16–25. Views expressed during workshops in October 2011 included:

- Young people moving from DLA to Personal Independence Payment at age 16 have specific needs and so should be a separate group—comparisons were made with the introduction of specialist child DLA teams which have been welcomed by children’s organisations;
- The Department should use learning from the assessment process for those aged over 25 to inform arrangements for children moving from DLA to PIP at age 16;
- People aged 16–25 should be the “last” group to be migrated from DLA to Personal Independence Payment so that processes have been well-tested beforehand;
- Young people should be encouraged to seek advice from a support organisation by signposting in claimant facing letters; and
- Face-to-face assessments should be conducted by someone with experience in working with young people.<sup>219</sup>

**176. We welcome the Government’s decision not to include child recipients under 16 years of age in the current DLA reforms. We believe that DLA for children should not be considered until the reassessment of working-age claimants has been completed and fully assessed. For clarity, we recommend that the Government give a commitment that it will conduct a full and separate consultation on any future changes to DLA relating to children.**

**177. We welcome the work DWP is undertaking on the specific needs of young disabled people aged 16 to 25. We recommend that this cohort should be the last to be migrated to the new benefit. We also believe there is a strong case for 16 to 18 year-olds to be treated as a distinct group from the rest of the “working age” population. One option which should be explored is for the reassessment at the time of the migration to PIP to take place in, and with the assistance of, the young person’s school or college.**

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<sup>219</sup> Department for Work and Pensions, *Personal Independence Payment—Policy briefing note: Young people*, November 2011, para 13.

## List of Recommendations

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1. As we have taken the relatively unusual step of conducting our inquiry while parliamentary scrutiny of the relevant Bill was under way, we trust that the Government will take our conclusions and recommendations into account in its formal consultation on the revised assessment criteria announced in January and then in drafting the relevant Regulations, which will set out the detailed structure and rules for PIP. (Paragraph 8)

### Policy objectives

2. We accept the argument that DLA requires reform. There is some evidence that the benefit has insufficiently clear criteria and is not always well understood. The complex claim form can also make it difficult for people to make a claim. We therefore support the Government's intention to address these issues. (Paragraph 42)
3. There is not a proper system for reviewing DLA awards: 24% of working-age DLA claimants have either had no change in or no review of their award for over a decade. While official fraud and error levels are comparatively low, there is evidence that around 11% of awards may be overpaid due to changes so gradual over time that claimants could not be expected to report a change in circumstances. We accept that there needs to be an appropriate, consistent and clear system for reviewing awards. (Paragraph 43)
4. Some witnesses believed that the necessary changes could have been made within the existing DLA structure. The Government's view is that this would have required changes to primary legislation and that there are advantages to a "fresh start". We agree that introducing a new benefit under a new legislative framework could offer the opportunity to improve support for disabled people while addressing the problems with DLA which the Government has identified. However, we believe the starting-point for reform should be to design a new benefit which meets its objectives in recognising the additional costs which disabled people incur. It is unfortunate that a background of budget cuts has created unnecessarily high levels of anxiety about this reform amongst DLA recipients. (Paragraph 44)
5. We are also concerned that the Government is basing its assumptions for the scope for reducing working-age caseload on the fact that there was growth of 29% in total DLA expenditure between 2002–03 and 2010–11. It is important to bear in mind that a substantial part of this growth arises from demographic change, including the increase in the number of people over state pension age who retain their DLA. PIP will only apply to working-age claimants, where growth is closer to 16% after taking account of demographic changes. We would welcome clarification from the Government on how these statistics can be reconciled with the savings assumption, in response to this Report. (Paragraph 45)



## Media coverage

6. The Government's view seems to be that the negative tone of press coverage of benefit claimants is unsurprising since it merely reflects the public mood about the integrity of the benefits system. However, the Government should not ignore the fact that public opinion can also be positively influenced by the media and we believe it should take the necessary steps to ensure that its own contribution to media stories about benefits is accurate and contextualised. (Paragraph 53)
7. While we accept that the Government does not control the editorial line taken by the media, we believe it should actively encourage accurate reporting of its own statistics on benefits. Direct quotations from Ministers can give undue credence to inaccurate or misleading reports. We recommend that DWP establishes internal protocols to ensure that significant statistical releases are accompanied by a press release setting out the context and providing background explanatory notes, together with quotations from Ministers where appropriate. (Paragraph 54)
8. We look forward to the publication of the new UK Disability Strategy. It provides an opportunity to address the apparent growth in negative perceptions about disability. We recommend that it contains proposals to tackle negative reporting of disability in the media and a Government strategy to get the message across that disabled people can and do make a positive contribution to society, very often as taxpayers. (Paragraph 58)

## Communication and consultation

9. The Chancellor of the Exchequer's announcement of the intention to reform DLA made the Government's communications task a difficult one. This difficult beginning was compounded by the poor initial consultation on the Green Paper which was not only shorter than recommended by the Government's own Code of Practice on Consultation but also took place over the Christmas period. The Bill was published before the consultation period ended, and well before the responses could be analysed. The Government's published response appeared not to reflect the full extent of respondents' concerns, and the full responses were not published. (Paragraph 63)
10. Since then, DWP has taken steps to involve disabled people in the process for devising and implementing PIP and this has proved to be effective to some extent. The Department has listened to many concerns: it dropped the proposals to end payment of the DLA mobility component for care home residents after the Low Review and to extend the three-month qualifying period under DLA to six months under PIP. It is important that DWP now puts even more effort into engaging disabled people in the introduction of PIP and that it clearly demonstrates the extent to which it has responded to their legitimate concerns. (Paragraph 64)

## Payment of DLA mobility component to care home residents

11. We welcome the Government's decision not to proceed with its plans for withdrawal of the DLA mobility component from residents of publicly-funded care homes. We

congratulate all involved in Lord Low of Dalston's review, which established a lack of evidence for the measure and a need for clear guidance to local authorities. We recommend that the Government now issues clear guidance about funding mobility needs and the role played by DLA and PIP mobility. We believe that this sequence of events clearly demonstrates the need for the Government to conduct thorough research, including detailed impact assessments, before the announcement of measures that could have a negative impact on disabled people. However, we accept that the Government listened to the representations of those affected. (Paragraph 71)

### Assessment of the impacts of the introduction of PIP

12. We believe that the Government cannot fully assess the potential knock-on impacts of DLA reform on other providers of services for disabled people. There is evidence to suggest that DLA plays an important role in helping recipients to manage their conditions, thereby reducing the need for other services. If a DLA recipient is found ineligible for PIP, yet still needs support, we would not agree with the Minister that there is already an adequate alternative package of support available to all current working-age recipients of DLA who may be affected by these reforms. (Paragraph 75)
13. DLA is unique in providing a universal benefit specifically designed to contribute to the extra costs of disability. If it is removed from some claimants who still have these extra costs, they are very likely to need to draw on services provided by other public agencies. We recommend that the Government carry out more detailed assessment of the wider impacts of DLA reform and consult further with local authorities and the NHS on the implications for their provision of services for disabled people, now that the updated impact assessment has been published. (Paragraph 76)
14. DWP has described other organisations' projections of the likely impact of DLA reform as "simply speculation". However, accurate analysis by interested bodies has been extremely difficult and claims have been made devoid of any factual basis in the absence of DWP impact assessments. Until very recently, the information released by the Government included no estimate of the number of people likely to be affected or any scenario modelling to indicate the likely impacts on different groups. (Paragraph 93)
15. The fact that Government information has been released at a late stage, and the consequent "speculation" by interested bodies, has also exacerbated public concern about the likely impacts of the introduction of PIP and worked against the Government's aim of reassuring disabled people that reform is intended to be a positive step for them. It is important that the Government and interested bodies learn from this. In future, major benefit reform proposals should be accompanied by detailed and comprehensive analysis of the likely impacts as soon as practicable. (Paragraph 94)
16. We are unable to ascertain, from the latest figures released by DWP in January, from which DLA rate combinations the projected PIP caseload reduction of 500,000 claimants will come and therefore which current DLA recipients are likely to have

their benefit withdrawn altogether. We recommend that, in its response to this Report, DWP sets out further case studies to show how the introduction of PIP is likely to affect current working-age recipients of each rate combination of DLA. (Paragraph 95)

### Qualifying period

17. We welcome the Government's decision to support a three-month qualifying period for PIP rather than extend it to six months. However, there is evidence of significant financial hardship caused during the current three-month DLA qualifying period, particularly for those with sudden onset conditions such as the loss of limbs after a car accident. We see no reason why claimants with sudden onset conditions, which medical evidence can show to be likely to last at least 12 months, should not receive support immediately. We recommend that DWP implements a facility for early eligibility which could operate in the same way as that for terminal illnesses. (Paragraph 102)

### The draft PIP eligibility criteria

18. We welcome the changes made to the first draft of the PIP assessment criteria. We believe they demonstrate that the Government has listened to concerns expressed by disabled people and their representatives. DWP deserves credit for the way it has involved them in the "co-production" approach it has adopted to the development of the PIP criteria. (Paragraph 128)
19. We fully support the Government's intention to ensure PIP is fairer, more consistent and takes a more holistic, "social model" account of the impacts of disability. One of the Government's declared aims for PIP is to improve on the assessment used for DLA. So far, mobility descriptors still concentrate heavily on ability to move a fixed distance and do not include barriers to accessing public transport, or the difficulties of some locations for individuals where routes to shops, public transport etc are particularly hilly or stepped. The PIP assessment criteria, as drafted, tend towards the medical model of disability. We recommend that, as part of the consultation with disability representative organisations on the second draft of the criteria now under way, the Government considers how activity descriptors could take account of the impact of such factors as housing, access to public transport and hilly locations. (Paragraph 129)
20. We recommend that the Government undertakes a further trial of the assessment criteria once they have been revised following the consultation and that the results of the trial are published before the criteria are laid down in Regulations under the Welfare Reform Bill. (Paragraph 130)

### PIP eligibility assessment

21. We were encouraged by the language used by the Minister in describing the PIP assessment as a "conversation" between claimant and assessor. It is vital that the PIP assessment does not take the same mechanistic approach, based on an inflexible computer system, originally adopted for the WCA in 2008. We believe that

healthcare professionals administering the assessments should take an empathetic approach that allows claimants to describe the impacts of their disabilities or health conditions on their everyday lives. We recommend that DWP sets out this principle in the published guidance for healthcare professionals on the assessment process. This approach will have implications for the time allowed for face-to-face assessments, which in turn must be reflected in the contract arrangements with the third party providers of the assessments. We would seek assurances from the Government that this will be taken into account in the contracting process. (Paragraph 139)

22. We agree with the Government that more reassessment of claims is necessary than has been the case with DLA. However, too frequent reassessment risks wasting public money and causing stress and anxiety to disabled people. The personal interview should play a part in assessing many PIP claimants. Face-to-face assessment should include the option for home visits where this is agreed to be appropriate. These steps may help to avoid cases going to appeal, with the accompanying costs and delays in resolving claims. (Paragraph 152)
23. We consider that there is a case for automatic entitlement for some claims. The WCA is being carried out annually in a number of cases, which can cause considerable stress for some people. The case for annual assessment is less compelling for PIP than for WCA which is judging people's ability to re-enter employment. We recommend that there should be flexibility in the frequency of PIP reassessment and that the Government monitors the impact of this. (Paragraph 153)

### Face-to-face assessments

24. Once the initial assessments for PIP have been completed in the first geographical area, we recommend that the Government looks again at the value of face-to-face assessments for PIP claims where the condition is severe and unlikely to change. The Government should reconsider whether, in many cases, reliance on medical evidence gathered over a period of time and based on detailed knowledge of the claimant would have more validity than the snapshot of a claimant's condition and its impacts on their ability to participate in society which can be gained in a relatively short interview with a healthcare professional who is not an expert in their condition. (Paragraph 154)

### Contracting

25. We recommend that DWP contracts with private companies for delivery of the PIP assessment directly link the payment of public funds to the production of reliable assessment reports that are "right first time". We welcome the framework approach which has now been adopted for benefit assessment contracts and request further details about how it will operate, in response to this Report. (Paragraph 159)
26. Experience with the Work Capability Assessment has demonstrated the need for large Government contracts with private suppliers which involve sensitive health and disability assessments to be properly monitored. We therefore request further information on how the Government plans to oversee and regulate the contracts for

the PIP assessments. We would also like to see the contractors' communication with individuals who are deaf-blind reflecting their communication barriers. (Paragraph 160)

### Implementation of PIP

27. The high number and cost of appeals in the original WCA process highlights the risk in introducing a new benefit assessment without full consultation and thorough testing. The challenge of accurately assessing DLA/PIP claims is arguably greater than incapacity benefit claims. The WCA simply assesses capacity to work. The PIP assessment will need to provide an accurate indication of the impact of complex conditions and combinations of conditions on participation in society in a variety of life contexts. It is therefore essential that DWP allows itself sufficient time to get the assessment right and to be able to convince disabled people and their representatives that this is the case. Implementation timescales should not be driven by artificial deadlines set by HM Treasury before the details of the reform were known. (Paragraph 165)
28. We welcome the Minister's confirmation that DWP does not intend to press ahead with a "big bang" approach to implementation of PIP and his commitment to begin with new claims only from April 2013. We note that the Government plans initially to introduce new PIP claims in one geographical area. The area should be selected on the basis of carefully defined criteria. The period prior to national roll-out should be used to prepare a methodology for monitoring the early lessons to emerge from implementation and to ensure that recommendations for changes can be made quickly, in consultation with interested bodies. (Paragraph 166)
29. We welcome the Government's decision to bring forward the first independent review of the PIP assessment to within two years of the assessment Regulations coming into force and to have a second independent review within four years of that date. (Paragraph 167)

### Reassessment of existing claims

30. As has been shown with the WCA/ESA process, reassessment of existing claims is even more complex and challenging than dealing with new claims. We therefore believe that reassessment of existing DLA claimants should only proceed once the Department is confident that the assessment is accurate. (Paragraph 168)
31. The phasing in of the reassessment for Personal Independence Payment should take account of the timing for individuals of the Work Capability Assessment for Employment and Support Allowance. There is likely to be a significant overlap between the two groups of claimants and many disabled people may already have had one or more WCAs by the time the PIP reassessment is introduced. The cumulative impact of frequent reassessment on a vulnerable group of people should not be underestimated. (Paragraph 170)

## Motability

32. We recommend that the Government clarifies, in response to this Report, which rate of PIP mobility component will confer eligibility for the Motability Scheme. It should also clarify whether a three-year lease for a Motability car, signed when the claimant was a recipient of higher rate DLA mobility component, will be terminated if that person is found ineligible for the Motability Scheme under PIP. We believe it is important for the Government to provide certainty on these issues before reassessment of the working-age DLA caseload commences. (Paragraph 172)

## Child and young adult recipients of DLA

33. We welcome the Government's decision not to include child recipients under 16 years of age in the current DLA reforms. We believe that DLA for children should not be considered until the reassessment of working-age claimants has been completed and fully assessed. For clarity, we recommend that the Government give a commitment that it will conduct a full and separate consultation on any future changes to DLA relating to children. (Paragraph 176)
34. We welcome the work DWP is undertaking on the specific needs of young disabled people aged 16 to 25. We recommend that this cohort should be the last to be migrated to the new benefit. We also believe there is a strong case for 16 to 18 year-olds to be treated as a distinct group from the rest of the "working age" population. One option which should be explored is for the reassessment at the time of the migration to PIP to take place in, and with the assistance of, the young person's school or college. (Paragraph 177)

## Formal Minutes

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The following declarations of interest relating to the inquiry were made:

### 19 October 2011

The Chair declared a pecuniary interest as a recipient of the mobility component of Disability Living Allowance.

### Wednesday 8 February 2012

Members present:

Dame Anne Begg, in the Chair

Harriett Baldwin	Glenda Jackson
Andrew Bingham	Brandon Lewis
Karen Bradley	Stephen Lloyd
Sheila Gilmore	Teresa Pearce
Mr Oliver Heald	

Draft Report (*Government support towards the additional living costs of working-age disabled people*), proposed by the Chair, brought up and read.

*Ordered*, That the draft Report be read a second time, paragraph by paragraph.

Paragraphs 1 to 59 read and agreed to.

Paragraph 60 read.

Amendment proposed, in the footnote at the end of the paragraph, after “Neil Coyle” to add “, a Labour Councillor in the London Borough of Southwark.” —(Harriett Baldwin.)

Question put, That the Amendment be made.

The Committee divided.

Ayes, 6	Noes, 3
Harriett Baldwin	Sheila Gilmore
Andrew Bingham	Glenda Jackson
Karen Bradley	Teresa Pearce
Mr Oliver Heald	
Brandon Lewis	
Stephen Lloyd	

Amendment agreed to.

Paragraph, as amended, agreed to.

Paragraphs 61 to 177 read and agreed to.

Summary agreed to.

*Resolved*, That the Report be the Seventh Report of the Committee to the House.

*Ordered*, That the Chair make the Report to the House.

*Ordered*, That embargoed copies of the Report be made available, in accordance with the provisions of Standing Order No. 134.

Written evidence was ordered to be reported to the House for printing with the Report (in addition to that ordered to be reported for publishing on 7 and 14 September, 2 November and 12 December 2011).

[Adjourned till Wednesday 22 February at 9.15 am.



## Witnesses

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### Wednesday 19 October 2011

Page

**Professor Steve Fothergill**, Centre for Regional Economic and Social Research, Sheffield Hallam University, **Sue Royston**, Social Policy Officer, Citizens Advice, **Professor Roy Sainsbury**, Social Policy Research Unit, University of York, and **Claudia Wood**, Head of Public Services and Welfare Programmes, Demos

Ev 1

### Wednesday 23 November 2011

**Amanda Batten**, National Autistic Society, **Neil Coyle**, Disability Alliance, **Paul Farmer**, Mind, **Geoff Fimister**, Royal National Institute of Blind People, and **Eugene Grant**, Scope

Ev 19

### Monday 12 December 2011

**Maria Miller MP**, Minister for Disabled People, **Dr James Bolton**, Deputy Chief Medical Adviser and **Simon Dawson**, Deputy Director, Independent Living and Office for Disability Issues, Department for Work and Pensions

Ev 39

## List of printed written evidence

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1	Centre for Mental Health, Hafal, Mental Health Foundation, Mind, Rethink Mental Illness, Royal College of Psychiatrists and the Scottish Association for Mental Health	Ev 53
2	Citizens Advice	Ev 58
3	Disability Benefits Consortium	Ev 61
4	Disability Alliance	Ev 67
5	Royal National Institute of Blind People, Action for Blind People, Guide Dogs, Sense, Visionary, National Blind Children's Society, SeeAbility and the National Federation of the Blind	Ev 72
6	Royal National Institute of Blind People	Ev 76
7	Scope	Ev 79
8	National Autistic Society	Ev 82; 87
9	Professor Steve Fothergill, Sheffield Hallam University	Ev 90
10	Department for Work and Pensions	Ev 94; 110
11	Professor Roy Sainsbury, University of York	Ev 110

## List of additional written evidence

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(published in Volume II on the Committee's website [www.parliament.uk/workpencom](http://www.parliament.uk/workpencom))

1	Mr Robert Leonard Brown	Ev w1
2	Kevin Kelleher	Ev w1
3	Martin Wilsher	Ev w3
4	Lisa Egan	Ev w5
5	Children's Society	Ev w7
6	Trades Union Congress (TUC)	Ev w10
7	National Centre for Independent Living (NCIL)	Ev w13
8	Mencap	Ev w14
9	Carers UK	Ev w19
10	Creative Support	Ev w23
11	Inclusion London	Ev w25
12	Sofie Rosemary Haidon	Ev w31
13	Oxfordshire Welfare Rights	Ev w32
14	Citizens Advice Scotland	Ev w39
15	North West Mental Health and Welfare Rights Group	Ev w43
16	Ecas	Ev w47
17	MS Society	Ev w51
18	Margery M Browning	Ev w55
19	Richmond Citizens Advice Bureau Service	Ev w58
20	Papworth Trust	Ev w58
21	Motor Neurone Disease Association	Ev w62
22	Every Disabled Child Matters	Ev w65
23	West Lothian Service Users Forum	Ev w69
24	CLIC Sargent	Ev w71
25	Law Centre (Northern Ireland)	Ev w75
26	Association of British Insurers	Ev w77
27	National AIDS Trust (NAT)	Ev w78
28	Community Mental Health Team (Kentish Town)	Ev w83
29	Local Government Association Social Security Advisers Group	Ev w85
30	Scottish Disability Equality Forum	Ev w90
31	National Deaf Children's Society	Ev w92
32	Headway – the brain injury association	Ev w96
33	ECDP	Ev w101
34	Yare Valley Citizens Advice Bureau	Ev w107
35	Macmillan Cancer Support	Ev w109
36	ENABLE Scotland	Ev w112
37	Danka Gordon	Ev w117
38	Sense	Ev w121
39	Contact a Family	Ev w125
40	South Lanarkshire Council Money Matters Service	Ev w128
41	Scottish Campaign on Welfare Reform	Ev w132

42	Motability	Ev w136
43	David Gillon	Ev w137
44	London Borough of Lambeth	Ev w140
45	Convention of Scottish Local Authorities (COSLA)	Ev w145
46	Arthur Rucker	Ev w147
47	Joint Committee on Mobility for Disabled People	Ev w153
48	Adults with Learning Disabilities Forum	Ev w155
49	Autism Consultancy Services	Ev w159

## List of Reports from the Committee during the current Parliament

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The reference number of the Government's response to each Report is printed in brackets after the HC printing number.

### Session 2010–12

First Report	Youth Unemployment and the Future Jobs Fund	HC 472 (HC 844)
Second Report	Changes to Housing Benefit announced in the June 2010 Budget	HC 469 (HC 845)
Third Report	Appointment of the Chair of the Social Security Advisory Committee	HC 904
Fourth Report	Work Programme: providers and contracting arrangements	HC 718 (HC 1438)
Fifth Report	The Government's proposed child maintenance reforms	HC 1047 (HC 1727)
Sixth Report	The role of incapacity benefit reassessment in helping claimants into employment	HC 1015 (HC 1641)



# Oral evidence

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## Taken before the Work and Pensions Committee on Wednesday 19 October 2011

Members present:

Dame Anne Begg, in the Chair

Debbie Abrahams  
Andrew Bingham  
Karen Bradley  
Kate Green

Mr Oliver Heald  
Glenda Jackson  
Brandon Lewis  
Stephen Lloyd

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### Examination of Witnesses

*Witnesses:* **Professor Steve Fothergill**, Centre for Regional Economic and Social Research, Sheffield Hallam University, **Sue Royston**, Social Policy Officer, Citizens Advice, **Professor Roy Sainsbury**, Research Director, Social Policy Research Unit, University of York, and **Claudia Wood**, Head of Public Services and Welfare Programme, Demos, gave evidence.

**Q1 Chair:** Before I ask you to introduce yourselves, can I just make a declaration? I am in receipt of the mobility element of DLA, so I thought I had better make that clear. I appreciate that it is not general for Members of Parliament to declare what benefits they are in receipt of, but in light of this particular inquiry, I thought it might be worth pointing that out. Can I ask each of you in turn to introduce yourself very briefly for the record?

**Professor Fothergill:** I am Steve Fothergill. I am a professor at Sheffield Hallam University.

**Sue Royston:** I am Sue Royston. I work for Citizens Advice as a social policy officer.

**Professor Sainsbury:** I am Roy Sainsbury. I head up the Welfare and Employment Research Group at the Social Policy Research Unit at the University of York.

**Claudia Wood:** I am Claudia Wood. I am Head of Public Services and Welfare at Demos.

**Q2 Chair:** Thank you very much. This is our first evidence session into the Government's plans contained in the Welfare Reform Bill that is going through Parliament to effectively end Disability Living Allowance (DLA) and introduce a new benefit called Personal Independence Payment (PIP). The first question really is, has the case been made for that essential abolition of one benefit and its replacement with a new benefit, or would it have been more sensible to reform, if reform is needed at all, the existing benefit? I wonder who would like to start. Is nobody going to speak first?

**Professor Sainsbury:** I could have a go. If you look at what the Government or DWP have said about the need for reform in their various documents, including the Impact Assessment, it boils down to just a few things: the poor understanding of the benefit, the lack of routine reassessment of claims, the inappropriate assessment criteria for certain impairments, and then the cost. They are the ones that are put forward.

I think everyone realises that DLA has its critics and no one would claim it is a perfect benefit, and it is always worth looking at benefits. When I looked at it, however, I thought the case was pretty weak apart from the need to save money, which was outweighed by the

actual benefit itself. Yes, there is evidence some people do not understand the benefit very much. That is pretty much the case for most benefits. Most people do not understand a benefit until they need to claim it, and then they find out about it. There is an argument that people confuse it with an out-of-work benefit. There is some evidence of that but it is not very conclusive. There is counter-evidence some people have a very good understanding and do realise this is a benefit that can keep them in work and that is helpful to them.

The argument that the assessment criteria for DLA have been very heavily weighted towards physical impairments rather than cognitive or sensory impairments has been well made over many, many years. I think DLA has evolved and changed over the years to try to encompass that. The new regulations, or the draft regulations, on PIP seem to go a bit further, so that is an argument well made.

There has never been any argument that it is not needed or it is not doing its job properly, and I find that interesting as an omission from all the policy documents. Everyone says, "DLA is to contribute to the cost of disability for people," and in all the arguments, I have never seen anyone argue it is not doing that. I referred in our submission from York to the research we were commissioned to do by the DWP, which is looking at the impact of DLA, and AA<sup>1</sup> as well, on peoples' lives. That came up with interesting evidence that I am happy to talk about, which I put in my submission, but it has got no place it seems in this argument. No one is saying this benefit is doing a bad job. I think the arguments for reform, apart from saving £2 billion or whatever, seem not very well established.

**Q3 Chair:** Could the arguments that the Government is using be fulfilled by just reforming the benefit, including the cost element, by bringing in slightly tighter criteria, and reassessing everyone or putting everyone through regular assessments? Would that not achieve the same ends but be a lot cheaper ultimately in terms of the bureaucracy?

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<sup>1</sup> Attendance Allowance

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**Professor Sainsbury:** I think probably the answer is yes. You could reform the DLA and deal with some of those weaknesses, deficiencies, criticisms of the benefit. The reassessment one in particular is put up as a strong argument for reform, but as far as I know there is no legal impediment to DWP reassessing the whole DLA caseload now if they wanted to—it is just a matter of resources. It is interesting they seem to be prepared to put in the resources for PIP to do lots of reassessments, but not to do it now. There is nothing to stop them as far as I know. You might take that up with DWP.

**Q4 Chair:** Can anybody explain why the replacement is taking place, rather than just a reform of the existing benefit?

**Sue Royston:** We are very concerned that it is about saving money and it would be quite difficult to save that amount of money just from DLA. Like Roy, we do think there are some problems with understanding the criteria for DLA and that causes problems for clients. We do not think care needs have ever been a really good proxy for extra costs. Despite welcoming what the Government says are the aims of PIP—making people more independent, welcoming the social model and so on—we are very concerned it is moving in the opposite direction to that. The aim of making it a more objective test moves away from any degree of personalisation. I think you are going to talk later about that in more detail, but we are very concerned PIP is actually moving in the wrong direction.

**Q5 Chair:** One of the things the Government says is DLA is a very complicated benefit to apply for and there is a lack of understanding. Now you did not mention simplicity in your opening remarks, Professor Sainsbury. Is that one of the reasons why it needs to be replaced? If it is replaced, is there a guarantee that the replacement would be simpler and easier to administer?

**Claudia Wood:** Personally, I do not think doing away with the existing system at quite a significant cost and replacing it with a whole new system is necessarily the most efficient way of streamlining an existing benefit a lot of people are familiar with and quite like. I agree with Professor Sainsbury that there are potentially other ways of correcting some of the problems with DLA. For example, we know there is a high disallowance rate, which suggests people are applying for it and they do not know whether they should or should not be. Those sorts of things can be dealt with quite neatly with improved advice and information, and improved awareness raising about what DLA is for, the fact that you can get it while you are in work, and all those sorts of things. Other benefits have had similar problems—for example, Working Tax Credits and Pension Credits—around the complexity and the poor take-up. Those have been dealt with in various ways: streamlining the assessment system, improving information and advice, and improving advocacy in the application process. Those things potentially could be cheaper and more efficiently done than having a new benefit.

**Q6 Chair:** I suspect the answer might be no, but has there been any work done on comparing the relative administrative costs of bringing in a new benefit as opposed to reforming the existing benefit?

**Professor Sainsbury:** I do not think there has been any work exactly matching what you have just said. There is an estimate in the papers it is going to cost £625 million—

**Claudia Wood:** £675 million.

**Professor Sainsbury:** Sorry, £675 million in transitional costs.

**Q7 Chair:** That would include costs for people so that they are not worse off, rather than just the administration costs presumably.

**Professor Sainsbury:** I think it is just the administration costs. That is how I read it as it is presented in the Impact Assessment—that is to save over £2 billion in benefit payments. When you say, “Is a benefit too complicated to understand?” most benefits are complicated, all benefits are complicated. When you compare the criteria for PIP with DLA there is not a lot of difference. I suspect the experience for the claimant is going to be pretty much the same: a very long form to fill in, other evidence to gather if you can, and with PIP you have the additional layer of a possible or almost mandatory interview with one of these new assessors. If it is a problem of complexity with DLA I cannot see that PIP deals with it, because it is trying to capture a lot of things, as so many benefits are. I cannot see that PIP is going to solve that complexity. It is not simple.

**Claudia Wood:** I would also suggest, because DLA is not means-tested, it is probably one of the simpler benefits that we have. The main complexity with the majority of benefits is how they interact with other benefits and with your income, and whether you become ineligible when you change your income. With DLA you do not have that complexity.

**Q8 Chair:** Is that not one of the Government’s arguments? Once people are on it they stay on it and nothing changes, and they are still there 20 years later even though their condition may have improved.

**Claudia Wood:** That is a reassessment issue, though, isn’t it?

**Professor Sainsbury:** It is an interesting argument. It is as if that is a very, very bad thing. People are entitled to a benefit, and many people have very chronic disabling conditions and health conditions that will last for 20 years. It is almost an automatic assumption that if someone stays on a benefit for a long time it is a bad thing, whereas another interpretation might be that is society reflecting someone’s needs and supporting them for a long time because that is what they need.

**Q9 Stephen Lloyd:** That is also back to the reassessment point that you are making. There should not be any reason why, currently under DLA, you could introduce the whole reassessment model every year if you wanted to.

**Professor Sainsbury:** There is no problem with that at all, as far as I can see. It is big numbers. I looked at the fraud report from 2005, which makes very

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interesting reading because, as you know, hardly any fraud exists in DLA and it never has done. Over 11% of cases in this fraud study were found to be wrong at the time they were reassessed, and they were wrong because people's circumstances had changed gradually. It was not that they had a change of circumstances like a sudden deterioration in health, or they had been given a new prosthesis or something, or they had gone into residential care, but a gradual change in health, which is most people's experience. So by the time they were looked at again, they were wrong.

I can see why they mention reassessments in the policy documents, because it is a problem. If you have 11% of the cases that are wrong, but no one is at fault through fraud, or claimant or official error, then reassessment is clearly the way to do it. But having identified the problem, as you say, there is no reason why it cannot be dealt with within DLA regulations.

**Q10 Glenda Jackson:** Is there not evidence to show that people who could and should claim DLA do not? I mean that is quite a sizable chunk.

**Professor Sainsbury:** That is a very interesting point because the issue of take-up is another missing element from the policy documents. It has always been thought of way back from 1992 onwards, that take-up is an issue. I am doing my good research bit here. I looked at the last effort to measure take-up of DLA, done in the late 1990s by DWP officials, and it was incredibly low. I think I cited the figures in my paper. The estimate of take-up of the mobility component was 50% to 70%, and the care component was 30% to 50%.

There are big margins of error there, and it is very difficult to measure take-up and to measure the eligible population that are not claiming. They do not exist anywhere in the data, so you have to go and find them. So it is very difficult to estimate and there are wide margins of error cited. But even so, I think it was a bit of a shocker at the time that they were so low, and efforts were made to increase take-up by publicity, etc.

**Q11 Glenda Jackson:** This does sort of link in to the issue of reassessment as well, doesn't it? You made the point that as a society surely we should be caring for people, but people out there do not know, so there is this dichotomy between reassessment and people actually being unaware. Presumably, those are things that could be changed now without needing necessarily to introduce another form of benefit. I think what I am working up to is, is there any evidence to say that is feasible and the cost would not be astronomical? Has anybody done any work on that?

**Professor Sainsbury:** Sorry, I am not quite sure what the question is exactly.

**Q12 Glenda Jackson:** I think what I am trying to say is that the Government's argument is that DLA is too complex and people do not understand it, for the reasons you gave, and the issue of money comes right at the bottom of the list. I think it has been established—has it not?—that reassessment could be

done now. But given the comparatively large percentage who do not even know they could and should be claiming DLA, what I am saying is this: would there not be a benefit as far as the proposed changes are concerned if we simply went for reassessment and greater advertising to the people who could and should claim?

**Claudia Wood:** Yes, but we have to bear in mind that the low take-up of the current benefit potentially works in the favour of the Government if they are looking to reduce overall costs of this benefit by 20%. In theory, by thinking that PIP will be more transparent and easily understood and more accessible and more people will apply for it, they are not going to reduce their 20% take-up rate. I do not think they have taken into account that the potential complexities of DLA means it actually has quite a low take-up rate, which is a benefit if you are thinking about keeping caseloads and costs down.

**Q13 Glenda Jackson:** I thought Professor Sainsbury said there is no evidence to show the actual qualifications necessary to claim PIP would be any less complex or any shorter than the current DLA form.

**Claudia Wood:** It will not, but if you look at the Impact Assessment on PIP they are very articulate about making this simpler, more transparent and raising awareness of it as a kind of "you will always know what you are entitled to before you apply" test. If they really try and promote it in that sense, they could potentially increase take-up.

**Q14 Glenda Jackson:** Surely, the promotion is to the existing claimants, and I am concerned with those people who could and should and do not.

**Claudia Wood:** I think if you promote it to disabled people as a population, you are not going to be able to not promote it to people who are not necessarily yet claiming it. It is hard to segment your target market and say, "We will cut down 20% of existing claimants, but in the furore of doing this, we may actually attract new claimants from the wider disabled population that had not been applying for DLA." There is a double-edged sword there.

**Chair:** I think we will move on.

**Q15 Debbie Abrahams:** Lovely to see you all. We have just talked about the unmet needs that we are currently experiencing in terms of DLA, and yet the Government is arguing that there has been such an increase in claimants over the last nearly 20 years, and there is a hidden suggestion there is something underlying this. What is the evidence around why there has been that growth, and are you also able to forecast, based on current understandings of claimants, how this will grow both for DLA and then thinking about PIP as well?

**Professor Fothergill:** Can I take this one, because I think it comes into my particular area of expertise and research? What I am about to say here may seem slightly unconventional, but it is supported by the evidence. The big increase in DLA claims over the last 20 years has very little to do with any deterioration in the underlying health or disability of

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the working age population. In fact, it has everything to do with the labour market. That comes through particularly clearly when you look at where the DLA claims are. We are not on about a phenomenon here that is spread evenly up and down the country. It is distinctly skewed.

In some of the older industrial areas of Britain—places like the Welsh Valleys, Merseyside, West Central Scotland, North East England—you will typically find something like 7% or 8% of all adults of working age are out of the labour market and receiving DLA as well as Incapacity Benefit (IB). If you come to the leafier suburban parts of southern England, it is around about 1% to 2%. What this is telling us is the big increase in DLA numbers is intimately bound up with the increase in Incapacity Benefit numbers we have had over the last two or three decades. What has gone on is that, in the difficult labour markets up and down Britain, we have had a diversion of people without work with health problems on to Incapacity Benefits rather than unemployment benefits.

Then many of those people on Incapacity Benefits have had to look around to see what they can do to maximise their household income. If they have considerable health problems or disabilities, they have then applied for DLA as well, and quite a high proportion have successfully qualified for DLA. So the process of causation, as I see it, and I think this is rooted in hard evidence and numbers, goes from a difficult labour market through to high Incapacity Benefit claims, and then on from that to high DLA claims amongst people of working age.

It has a further twist to it as well. Once you are on DLA, even if you then successfully return to work you do not necessarily have to automatically give up your DLA. DLA is supposed to offset the costs of disability whether you are in work or not. What you also find is that the adults of working age who are in work and receive DLA are concentrated in exactly the same older industrial areas and weak labour markets as the adults who are out of work on DLA. That is because through time some do manage to re-engage with the labour market.

Then a further twist beyond that is once people reach state pension age they lose their entitlement to IB and they go on to State Pension, but again they do not lose their entitlement to DLA. That has been carried forward into a generation that are now beyond State Pension age. So it is the weak labour markets in certain parts of Britain that is really driving all of this. That is what I would say.

**Q16 Debbie Abrahams:** Can I follow that up then? So you are saying the key driver is around labour market conditions.

**Professor Fothergill:** Yes.

**Q17 Debbie Abrahams:** So what proportion then of DLA claimants/recipients would you say that relates to? What proportion relates to people who have long-term if not lifelong conditions that will never change?

**Professor Fothergill:** I am not saying people who get DLA who are out of work are doing it in any sense fraudulently. They have real health problems and real

disabilities. But ill health and disability has never been an absolute bar to working. What you find in the stronger labour markets of southern England is that people with health problems and disabilities largely do work. I mean there are still some who find their health or disability obstacles too formidable to secure employment. But in weaker labour markets, poor health or disability, along with low skills and advancing years, is one of the great discriminators that determines who is going to hang on in the labour market and who is not. So I am not in any sense saying there is fraud, but I am saying that a significant proportion of those on DLA in the weaker labour markets of Britain would almost certainly have been in work in a stronger local economy.

**Q18 Debbie Abrahams:** Can you quantify significant proportion?

**Professor Fothergill:** Not off the top of my head, but my hunch would be that you are talking about probably half.

**Stephen Lloyd:** Good Lord.

**Q19 Brandon Lewis:** Just on that point, I am interested in the comments you have just made. It builds on some thoughts from when you presented to a group I was in on the coastal town employment levels, which have some similar issues. If other reforms that are going on at the same time, such as the Work Programme, were successful, and social mobility and employment levels increased in those areas over a period of time, would you take the view that a reduction would therefore occur in those areas, with people getting back into a healthier work environment, if you like, in the sense there is more employment in those areas where the Work Programme is successful. There could be a gradual drop off in the people who would, if it was there, claim DLA, because they are now in a better working environment.

**Professor Fothergill:** To get people back into work you have to have two things going on. You have to have support for the individuals. I do not think we should ever underestimate the scale of the support individuals need if they are on IB or particularly if they are on DLA. They have real physical and mental obstacles to working that need addressing. You need that help for individuals and that is one of the things the Work Programme is designed to provide. But you also need the jobs out there.

At the present juncture, my suspicion would be that the Work Programme may have some chances of success in the parts of Britain where the labour market is still tolerably buoyant, such as large parts of southern England and London. But it is going to have huge difficulties in making any inroads into either the IB or the DLA numbers in somewhere like the Welsh Valleys. It is precisely in places like the Welsh Valleys where you find by far and away the highest proportion of adults of working age on DLA and IB.

**Q20 Brandon Lewis:** If it was successful and there was the ability for jobs to be created that the Work Programme helped people into, you are saying that there could be that tail-off in the claimant level



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because people are getting back into that work opportunity. I am also conscious that some of the providers of the Work Programme are saying that in some of those areas you have mentioned, their problem is not demand; it is supply and getting people to actually work, but that is their issue. But if those jobs are there, the Work Programme works, so that could see a tail-off.

**Professor Fothergill:** If jobs are there, you can bring down benefit numbers, but it happens in a certain order. The first people who re-enter employment are those closest to the labour market, so they tend to be the people on Jobseeker's Allowance. That is what happened in the first part of the long boom we had before the present recession. Once you get numbers on Jobseeker's Allowance down to historically low levels, you then begin to erode the Incapacity Benefit numbers.

We saw that happening from around about 2003 onwards. It was not eroded as much as it should have been, but that is a different story, perhaps because the support was not there. Unfortunately, the way I would see it, though, is that the very last group who will tend to get brought back into the labour market are those not only on Incapacity Benefit but also the DLA group within the Incapacity Benefit claimant group. They do have somewhat greater physical or mental obstacles to working. But the evidence of large parts of southern England does say that if the economy is strong enough people do not hang around on sickness and disability benefits—they mostly stay in work.

**Q21 Oliver Heald:** Is it not also the case that the areas you are talking about are areas with poorer health? How do you justify pinning this on the labour market?

**Professor Fothergill:** Yes, absolutely. There are poor underlying levels of health, and I think you would always find that in some of the older industrial areas the Incapacity Benefit claimant rate was higher than in the leafier parts of southern England. If you go back a generation or so ago, before there was the huge job destruction in some of these places, you had much lower rates of Incapacity Benefit claims. We did not have DLA back in the 1980s, but far fewer people were out of the labour market on sickness benefits even though in that era more of the adult population had been exposed to, for example, the harmful effects of working down the pits, in the steelworks, or in heavy industry. It was only when the jobs disappeared that you began to get this surge in the numbers out of the labour market on Incapacity Benefits.

**Q22 Oliver Heald:** That is not to do with the structure of benefits, which of course was different in those days.

**Professor Fothergill:** It is in the sense that, if you are going to be out of work, the best benefits to be on long term have tended to be Incapacity Benefits, in the sense that financially in most household circumstances you are marginally better off being on IB rather than Jobseeker's Allowance. You also have fewer demands placed on you. You do not have to sign on every fortnight and you do not have to look for work. Those would be quite onerous demands if you know you

also have health problems, and out there in the world employers are not going to look at you because of your poor qualifications, your age and your poor health.

**Q23 Oliver Heald:** Unemployment is bad for your health anyway, isn't it? I mean it leads to depression, for example.

**Professor Fothergill:** It does. There is quite a lot of evidence that, once on Incapacity Benefit, a single health problem can then multiply. Many people who may go on initially for physical reasons develop things like depression as well after an extended period out of the labour market.

**Q24 Karen Bradley:** Picking up on what Brandon was saying just to clarify, are you suggesting that the evidence is that for people on IB and DLA who get back into work, because DLA is a benefit to enable them to live and to support them with their disability, the DLA claims will not go down even if the IB claims go down?

**Professor Fothergill:** We have not had a system where DLA has been automatically reassessed periodically, and reassessment is not necessarily triggered by re-entering employment. If you do successfully move from being on Incapacity Benefit with DLA into work, you can carry your DLA forward. That has resulted in the situation where exactly the same areas that have high DLA claims out of work have high DLA claims in work as well.

**Q25 Karen Bradley:** So I am correct in understanding that, if we had the Work Programme, for example, and there were jobs available, we should not expect to see a sharp drop in DLA claims? They would still carry on at a plateau?

**Professor Fothergill:** It would not happen automatically, but of course the introduction of regular reassessment in the Personal Independence Payment system would presumably tend to begin to filter out some of those people who have managed to go back into employment. At least a proportion will have done so because their underlying health problems or disabilities have eased.

**Q26 Chair:** Does your analysis therefore explain the low take-up we have heard about already, because basically it is an economic driver? In other words, when a family or an individual's income drops because they are out of work, they look around to see how else they might maximise their income, realise they have a disability and apply for DLA, and get it and keep it, whereas someone who is in work or living in a more affluent family does not even think of applying for it at all, even though they may have the same level of disability as the person who has been out of work.

**Professor Fothergill:** I think that is a very plausible theory that is consistent with the evidence.

**Q27 Chair:** So the take-up is high in the areas you are talking about.

**Professor Fothergill:** Yes.

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**Q28 Chair:** But the take-up is low in the more affluent areas.

**Professor Fothergill:** Yes.

**Q29 Chair:** When I applied for mobility allowance, I was a student, and had I become as disabled as I am once I was an MP, would I have applied for it? Probably not. I suppose that is very much an economic determiner of who applies.

**Professor Fothergill:** Yes, if people with health problems or disabilities do manage to get by successfully in work they probably do not need to turn their attention to what they can get out of the benefit system. If we are honest, we are not talking about terribly large amounts on the lower rates of, for example, the mobility payments. This is only £17 to £18 a week. It is not going to be a central thing in your existence.

**Claudia Wood:** I just wanted to point out that we have to be careful not to think of DLA as an out-of-work benefit and that therefore increasing employment will resolve the number of DLA claimants. No one knows exactly how many DLA claimants work, but polling suggests it is around 27%. The DWP's own research from last year suggested that a lot of people used DLA to keep in work. They use it for childcare and transport costs to enable them to stay in the labour market. There were suggestions that, if we think about it as slightly more of a benefit for people who are not working to prop up their income, there is a risk of assuming that once people are in work they will not need DLA or PIP. We have to remember that additional top-up of income is there for those additional costs that disabled people have to get into work and stay in work. I think we cannot lose sight of that.

**Professor Sainsbury:** I just wanted to add to what Steve said about the drivers for the increase in numbers, because the increase in the numbers is very striking, and it does deserve some sort of answer. A piece of work that came out earlier this year, again by DWP statisticians, tried to unpick some of this. From 2002–03 to now, there had been a 29% increase in the numbers on DLA, which I must admit struck me as very high. But this analysis attributed a third of that growth just to demographic features like the ageing population and the growth in the post-retirement age numbers on DLA, so some of that growth went away. There is no reason to think DLA is doing a bad job or anything like that; it cannot be criticised for that increase.

The remaining increase was a genuine increase, and Steve has given one of the drivers for it. The analysis also draws attention to the big growth in the numbers of young people on DLA. There are a big spikes in the numbers of young people claiming DLA—teenagers and younger. This suggests to me the reason those numbers are increasing is because young children are living longer with severe disabling conditions, and probably take-up campaigns by disability organisations are having an effect. We know some representative organisations around specific disabilities and child disabilities are very, very effective. They will campaign, lobby and advertise.

**Q30 Stephen Lloyd:** I think there is another reason. As Professor Fothergill was saying, in those areas where there is high employment, historically you have a higher percentage of people on DLA. One of the challenges is unfortunately there has been very high youth unemployment for the last few years, and that might fit with Professor Fothergill's premise that consequently you are going to have a spike in DLA.

**Professor Fothergill:** Yes and no on that one, actually. Although the increases might have been quite sharp amongst younger people, we do need to bear in mind the DLA stock of claimants is still very skewed towards the older age groups. I am just looking at some figures here, admittedly for 2008, where the stock of DLA claimants who were also claiming IB, so were out of work, amongst the under-25s is only 75,000 compared with around 400,000 who were over 55. I do think we need to keep all of this in perspective. Generally speaking, ill health and disability does rise with age, irrespective of people who are coming through from childhood with disabilities. So it is this particular group towards the back end of their working lives who are often, if we are honest, discriminated against because of their age. If they then have poor qualifications and health problems, their chances of finding work are negligible. They have to maximise their benefit package. They look around and it becomes IB and DLA.

**Q31 Glenda Jackson:** Surely, one of the possible reasons for the spike in the number of young claimants has been simple improvements in medicine.

**Claudia Wood:** Absolutely.

**Q32 Glenda Jackson:** Children who normally would have died are now living.

**Professor Sainsbury:** There are a variety of reasons why these numbers have gone up and by so much, but in all this analysis I cannot see there is a bad reason for the increase. They are all understandable reasons. In some ways the increase could be seen as a success, given the low take-up that people have been concerned about for a long time.

**Claudia Wood:** And obviously the success of modern medicine.

**Q33 Andrew Bingham:** Claudia, you said broadly that when people get back into work they are using DLA for things like childcare. My question is: do we think that is appropriate? Obviously, there will be people who are in work who are not on DLA who have to find their childcare costs, so is that appropriate use of the benefit? Also, you remarked about the increase in the younger cohort, which disturbs me greatly. Have we got the figures to see whether that mirrors the regional variations in the wider take-up of DLA?

**Professor Sainsbury:** I will give the quick answer to that second point. The analysis from the DWP does not give that.

**Andrew Bingham:** Right, okay.

**Professor Sainsbury:** I do not know if we know.

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**Q34 Andrew Bingham:** No, I was just curious given what Professor Fothergill had said about the regional variations.

**Claudia Wood:** DLA and PIP are not ring-fenced. You can spend it on whatever you want. One of the great things about this benefit is that you spend it on any additional costs you have related to a disability. Disabled parents may well have greater childcare needs and childcare costs than non-disabled parents.

**Q35 Andrew Bingham:** In what circumstances?

**Claudia Wood:** For example, if you have been at work all day and you are in a wheelchair, when you get home you need help with bathing your child and putting them to bed. Disabled parents often need more help in general, and having that childcare cost is related to your disability or your inability to lift your child as they get bigger and older, transport to school and all those sorts of things. There is nothing in the rules around DLA or the new proposed PIP that suggests you can only spend it on things that are related to—

**Andrew Bingham:** I was not suggesting that; it just caught my attention when you remarked on that, and I thought actually there are people who are not on DLA who will have childcare costs. It was the difference.

**Q36 Karen Bradley:** Presumably, they will have those childcare costs whether they are in work or out of work. If they have a need for childcare support because of their disability, it is irrespective of whether they are in work or not.

**Claudia Wood:** Yes, of course. One of the things that DWP found—it was done by Corden *et al*, if you want to look at it—was that a lot of working disabled parents said they found childcare quite costly, and they were using it and often needed it when they got home, because they were too tired and wiped out to get their children into bed after a day working. So it was not just childcare for non-disabled people, but that additional bit.

**Q37 Andrew Bingham:** That was the point I was trying to get to—the difference in the childcare costs that somebody in receipt of DLA would have as opposed to somebody who does not qualify.

**Chair:** I am going to bring Sue in, and then back to Professor Sainsbury.

**Sue Royston:** Just on that point, what clients tell us is that, if somebody has multiple sclerosis for example, if they have a part-time job two days a week, that wipes them out, so they need a lot more help with chores, ironing, washing and cooking. If they had been staying at home and not working, they could have perhaps managed those challenges. The other great cost that we find disabled people have regarding going into work is the transport to work, which is not usually covered by things such as Access to Work. We hear a lot more evidence about people using the extra help they get for taxis to work, *etc*.

Regarding the fact this is not a small amount, people on a low income would be entitled to the disability element of Working Tax Credit. The DLA will passport them to that, and the two together will make

a quite significant difference to their income and will enable them to go into work. One of the things we are concerned about with PIP is if you remove that lower rate in effect, you are going to lose that passporting, and those people are going to find it increasingly difficult to go into work.

I just wanted to come back to something Steve said. We want to stress we see no evidence at all that on the whole people are receiving DLA that do not need it. If you look at the test for DLA, you need quite a lot of care to qualify, or for mobility. So these are people with very significant problems that do have considerably extra costs. There is a problem with take-up, and I did want to say about the complexity because there is an area where DLA is actually complex. It is about care in association with bodily functions, and it is very difficult for people sometimes to understand that. So there is a valid criticism of DLA there, but there would be ways round that.

For instance, we had a client with a child that was severely visually impaired. The parents in fact got help from the health visitor, and put down lots of care needs, but they were about feeding and so on. They were refused DLA. Of course, with a child that is severely visually impaired, you have to structure the language a lot more. Whereas you would point out a dog across the road and say “dog” to develop the child’s language, you would have to push the pushchair over and think about how you were going to get across the concept of the dog to the child. That counts as care, but a parent would not necessarily see that. So something could be done.

Every severely visually impaired child is going to have that need. The decision maker should not be refusing that child because the parent has not written that down. At the very least, they should be ringing up the parents and saying, “Well, don’t you have to structure the language more?” So there are things that could be done. There are levels of complexity we did not talk about, but things could be structured to get rid of that complexity. If you structured it in that way so people knew who were going to be entitled, then take-up would be better.

**Chair:** I am very conscious of the time.

**Sue Royston:** Sorry.

**Chair:** I just want to know if Debbie has actually finished her line of questioning.

**Debbie Abrahams:** I think I have actually. It has probably been covered.

**Q38 Chair:** Everything has been covered. Professor Fothergill now.

**Professor Fothergill:** Could I just come on in this point as to whether or not DLA is going to people who should not be getting it. When I first came into this area, I was struck by how demanding the tests are for eligibility for DLA. It seemed to me that, if the rules are being properly applied at the present point in time, there is little reason to suppose anyone who is moving onto DLA does not have very considerable mobility or care needs, even to get the lower rate. But what does seem to me to be missing from the system as it has operated to date is that there has been no regular reassessment. In practice, about a third of the awards that are made by DWP are indefinite—in other

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words, for life. What that feeds through to over a period of time, because some of the people with short-term awards do drop out after a period, is that two-thirds of the entire stock of DLA claimants currently have that entitlement for life. So they can continue to get DLA on the basis of a medical assessment that might be 10, 15, even 20 years out of date. That is the area where I think there is a distinct question mark about whether the present system operates properly.

**Q39 Stephen Lloyd:** I am now going to move on to PIPs. The Government predicts that the working age PIP reform will result in a 20% reduction in expenditure by 2015 to 2016. You have touched on that a wee bit, but just on that premise, do you think that is a realistic target based on the approach they are going to be doing with PIP?

**Professor Sainsbury:** This is a really interesting aspect of all this because the 20% reduction in expenditure was mentioned last year, I think, in the Budget statements, before any consultation documents came out. And I wonder where that figure came from, because I have no idea. I can understand it as a target; if the Treasury wants to save 20%, then that makes sense. But to say it will without knowing what the criteria are going to be, what the thresholds are going to be on the points, what the rates of the new benefit are going to be, I really am at a loss to know where that 20% came from. As I say, if it is a target that is entirely understandable, because you then adjust your threshold rates, your points and your rates of benefit for each component, and you could achieve 20%. But you cannot say this will achieve a 20% target from the start. I think it is a very odd bit of the story.

**Q40 Stephen Lloyd:** Before I come to you, Claudia, I wonder if their premise underpinning that, not target as you say but apparent reality, is that the model they have used around re-assessment may well mean they think about 20% are going to drop out through re-assessment. That could be one possible answer. Claudia?

**Claudia Wood:** I took the 20% the same way as Professor Sainsbury did. Essentially, it is a slightly arbitrary target and they feel 20% of DLA claimants do not deserve it or that seems about the right level of saving, whatever the reason is.

**Q41 Andrew Bingham:** I think that is a very strong comment, to say that 20% do not deserve it.

**Claudia Wood:** Well, maybe that is the sort of level of saving they want to achieve, and I think you can retrospectively set your test to achieve that. It is not impossible to achieve; you just have to essentially make your test 20% harder. You can pilot it and reduce your numbers. So it is certainly achievable, but you could not say that 20% was based on anything. They are not psychic; they had not set the new PIP test up when that 20% was agreed, and I assume it is more of a savings target than anything more evidence based.

**Q42 Chair:** If you get rid of the lower tier, does that not add up to about 20%?

**Claudia Wood:** No.

**Sue Royston:** I have done some calculations on that and we think it is about 8%. So that is significant extra savings that have got to be made.

**Q43 Oliver Heald:** Yes, but of course the National Benefit Review did show about 11.5% overpayment. So if you take the two figures together, you are at about 20%.

**Professor Fothergill:** There is perhaps a salutary lesson to be gained from looking across at what has happened with the Work Capability Assessment for Incapacity Benefit. The initial assessments there by DWP were just 10% of people qualifying for IB would not qualify under the Work Capability Assessment for Employment and Support Allowance. In practice that figure has turned out to be at least 30%. We could be looking at a very much larger reduction in the numbers qualifying for DLA, depending on exactly how the criteria are set and interpreted. That 20% could turn out to be 40% if the experience of the Work Capability Assessment is anything to go by.

**Q44 Stephen Lloyd:** And also perhaps adding to that, going back to what you and others have just been saying, DLA by its very nature has not had any reassessment.

**Professor Fothergill:** Time-limited claims have been reassessed. If people are awarded just it for three years, then at the end of the three years it is reassessed.

**Q45 Stephen Lloyd:** In comparison with other benefits there has been very, very little reassessment. So I think where the Government's model is coming from, similar to with the WCA, is when you have that reassessment, there will be a sharp drop-off. But if anything, it strikes me then as even more odd that they are bothering to spend £670 million on a new benefit. Why do we not just start assessing people on DLA? But anyway, we have covered that.

Moving on to my next point, because we have a lot to get through, from an empirical evidence perspective is it possible with the data that you have received, or that you have been working on, to accurately assess the likely impact of a cut in DLA or PIP expenditure? Have we got any evidence of what you think will be the consequence?

**Professor Sainsbury:** It is a good question, but a very hard one to answer. We do not know where these cuts are going to come and who is not going to get the benefit. If we think in the future existing claimants of DLA will be reassessed and those on the lower tiers will probably lose, then we can say that you could easily measure the financial impact on those individuals and families. There will be an impact there. How that feeds through to their lives will be very different for individuals—what they spend their money on, *etc.* So there will be an impact, and I suspect you would be able to do it, but you cannot do that now because we do not know exactly where the cuts are going to come.

**Glenda Jackson:** We do.

**Professor Sainsbury:** No, sorry, we do not know the levels.

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**Q46 Glenda Jackson:** Not in hard statistical terms, but we are all, I am sure in every constituency, receiving notices from people, for example, of closures. My big one is day centres for certainly adults who are claiming DLA, and they are going to close. Those people are severely disabled, there is no way they are going to be able to form a company and provide a day care centre by grouping together. So there are already implications in train. Those kind of external supports that at the moment are provided by society, which are not individually bought necessarily by someone claiming DLA, are going.

**Professor Sainsbury:** I cannot disagree with that. I thought the question was slightly different though.

**Glenda Jackson:** Sorry.

**Chair:** I think we have questions that will wrap some of that up anyway.

**Q47 Stephen Lloyd:** Well, anyway, Sue?

**Sue Royston:** The Government have said they want to protect those with the highest level of impairment, but obviously the people with the highest level of impairment get the most money. So you are cutting more people if you are cutting the people on the lower level. We are particularly concerned, right throughout the Welfare Reform Bill, with the people with significant but not the most severe level of impairment. They are going to be the people who drop out of PIP and out of ESA because the descriptors have tightened on ESA. At the moment, if you are on lower rate care, you would get the disability element of Working Tax Credit.

The gateway through Universal Credit is going to be through ESA, so if they do not meet the descriptors there they will not get any extra help compared with somebody without a disability. So people with quite substantial levels of disability throughout the system are going to lose all the help, and it will be the same group that are going to lose throughout. They in effect are going to lose any sort of marker that says they are disabled even though they do have an impairment, which even more importantly, in some ways, will also mean that they cannot access things from a local authority—travel passes, leisure passes.

**Glenda Jackson:** It is already going on.

**Q48 Stephen Lloyd:** Those are very important points. How has the DWP responded specifically to you and others when you have made those very particular points—that the middle range group with pretty severe disabilities are going to lose out all the way down the piece. How are they are responding to you?

**Sue Royston:** I do not think they deny it. We have not had a firm response, but I think it is Government policy to help those with the highest level of impairment, and therefore the people that drop out of the system are going to be those with the less high level of impairment.

**Professor Sainsbury:** It is really interesting to reflect on why we had DLA as it was in 1992. The lower rate of care was introduced at that time because of research by OPCS, a disability survey in the late 1980s that showed people with less severe disabilities had significant costs because of their disability that

were not met by the system as it was then with the old Attendance Allowance and Mobility Allowance. So it was a positive response to recognising there were costs of disability that were not addressed by the benefit system at the time, and DLA was reformed and a lower rate came in.

I have seen no evidence to suggest those costs have gone down for that group of people, or disappeared. They are still there. But this is the group to whom in the future society will say, “We recognise you have extra costs because of your disability, and we are not going to meet them.”

**Q49 Oliver Heald:** Of course, when we introduced that in 1992, the estimate was that there were about 140,000 people who would need this help. In fact, I think it is 900,000—isn’t it?—who are receiving it. So isn’t it right for the Government to just re-examine this?

**Glenda Jackson:** But what followed on from that—

**Chair:** Glenda, I think we should let our witnesses answer the questions, rather than discussing it across the Committee.

**Professor Fothergill:** Could I just try to take up directly this question of who is the reduction in expenditure on DLA to impact on? The DWP’s own assessment is that DLA is principally but not exclusively received by households with below average income. Around about two-thirds of DLA goes to households that are below the average, though actually the very, very poorest households, the worst 10%, tend not to be great recipients of DLA. What we also need to bear in mind is there is more than one thing happening simultaneously here, as has been mentioned.

The reduction in DLA will often hit the very same individuals and households who can expect to lose entitlement to Employment and Support Allowance, as Incapacity Benefit is becoming. They will lose it either because they do not qualify for ESA, or because they find their ESA is means-tested after one year, and other sources of household income then disqualify them from getting ESA. So for at least a proportion of people this is going to be a double whammy in terms of benefit loss, and that is going to be concentrated in the lower half of the income scale, if not always necessarily right at the bottom.

**Claudia Wood:** I just wanted to point out some research that I carried out last year looking at the drivers of disability costs. We did a survey of about 850 disabled people to look at what they were spending and how that related to the amount of hours of care they needed every week. We did not find a strong correlation between the amount of care you need every week and your disability-related living costs. So we do have to think about what PIP is trying to target. If PIP is to compensate people partially for the costs of living with a disability, should we not be targeting the people with the greatest costs, not necessarily the greatest needs? They do not necessarily coincide.

If we reserve it just for people with the greatest needs, there are going to be people there who have complex conditions who may have very well adapted homes, a partner who supports them and accessible transport,

and do not necessarily have huge living costs. So there is a mismatch on the targeting there, and that could be inefficient for the Government. It is not just about people with low needs and high costs, but also about people with high needs and low costs getting more than they necessarily need. I think that is important.

**Q50 Karen Bradley:** I want to turn now to the overlap and what evidence there is as to whether DLA is providing help for people that also are being provided with help from, for example, social services at local authority level for the same care.

**Sue Royston:** Certainly, what we have seen is that people sometimes do use their DLA to get specialist equipment or therapies, but usually because they are not available. A Macmillan advisor told us she asked a Macmillan nurse why all her clients were having to buy extra pads, and she was told it was because the NHS was rationing the pads, and so people were being told they had to wait until the pads were thoroughly soaked. If it is about independence; those people were embarrassed to go out in that situation, and so the DLA is actually helping them to be independent if they use it. That is one small example, but it is the sort of thing where people will use their DLA because things are not available that are currently thought to be so in other places, and that prevents them from being independent and socially included.

**Claudia Wood:** Additionally, if you look at the Dilnot Commission Report around social care funding that came out in July, it explicitly was saying people should be using their DLA for things that fall beneath the eligibility criteria of social care if you are a self-funder or if you do not have substantial and critical needs but you still have some care needs. If you have moderate needs, that is still a substantial amount of care you need; you are not going to get anything from local authorities necessarily, and your DLA can top up on that shortfall.

Ironically, I think the PIP assessment focusing the funding more on higher need, if you look at the descriptors of the assessment, would suggest you are increasing overlap between social care and benefits by pushing it up towards the acute end of the needs spectrum. We were talking about the double whammy; essentially people below the eligibility of local authority social care will also be below the eligibility of DLA and PIP.

**Q51 Karen Bradley:** So could you see a situation where local authorities start to withdraw free services that they consider are covered by the DWP DLA or PIP payment?

**Claudia Wood:** At the moment, I think about a quarter of local authorities ask people to contribute their DLA towards their care costs, and the majority take it into account as a form of income. So it is not as if there is not an interrelation there.

**Professor Sainsbury:** The policy overlap in social care is very interesting because DLA is not a social care benefit. It is very easy to conflate the two because we have proxy measures for measuring the cost of disability, and we have care and mobility. It is something that has got fixed, I think, in people's minds—that this is a benefit for social care. I think

that is where Wanless got it wrong some years ago by assuming that was what it was for. It is not, and what people spend it on and use it for is much, much wider than social care.

I will correct my figures if I get a chance later, but I think I am right in saying studies have shown recently that only about a quarter of people spend their DLA on what we understand as physical social care—people helping them dress, wash, *etc.* Most expenditure goes on a huge range of other things, such as gardening, dog walkers, paying for the television licence, *etc.*, which enhances people's lives and offsets the cost of their disability, because costs of disability are not just financial costs. If we are going to take the social model seriously, there are social costs of disability.

So when we did our research some years ago and found people using their DLA very imaginatively, it blew our minds. If I can give just a couple of examples: the lady who did spend her DLA on a dog walker, because if she did not, because she could not get out, she could not have a dog. Her dog was her friend, and her well-being was enhanced accordingly. Another example is a lady who spent it on a carpet. You think, "What, on a carpet?" She said, "Yes, now I have a new carpet I feel confident enough to ask my neighbours and friends round for a cup of tea." You may think these are incredibly imaginative uses of DLA, which we should all be proud of in some ways, rather than saying, "You have to spend it on extra food, extra fuel or extra heating," or something like that.

**Glenda Jackson:** Absolutely.

**Q52 Stephen Lloyd:** So what do you think then when the Government originally made the announcement of removing the mobility component for residents of care homes? There was an outcry on the Coalition backbenches as well as in the Opposition. The Government reined back and said that they would not do it for a year or two, but clearly their direction of travel is, "Listen, social services should be doing this, and DLA mobility means that social services are not doing it. That is not right because social services should be doing it." So what do you think of their whole direction of travel?

**Professor Sainsbury:** Just to reiterate that example: if someone's mobility is restricted, they might use their DLA to compensate in some way—not actually use it for travel even, but get the big telly in. This is what people do so they have a nicer life. They cannot get out and they do not want to go out particularly, but the social costs of having difficulty with mobility are offset by having a nice telly because their wellbeing goes up.

So the point you are making there is about people in residential care homes, isn't it?

**Stephen Lloyd:** Correct.

**Professor Sainsbury:** There was an outcry about restricting the mobility components of that group of people, and you are right—the Government is now treading water on that for a few years and reconsidering it. But again, it is sort of misunderstanding of what this benefit was originally about, still is about it seems to me, and how it is

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actually used to enhance people's lives and offset the social and financial costs of disability.

**Q53 Karen Bradley:** Do you feel that there is a communication exercise the Government has to do on DLA, and obviously PIP in the future, to make people aware and understand what they envisage DLA will be used for?

**Professor Sainsbury:** I do not think the Government does envisage what DLA should be used for, do they? I have never heard a statement from any Government to say how you should use your DLA. I mean it is the best personal budget you could have, isn't it? It is like having a wage. No one is telling me how to spend my wages.

**Q54 Karen Bradley:** Maybe the communication should be that it is free for people to spend as they see fit.

**Professor Sainsbury:** That is the message. I think it is only confused when you get other debates about paying for social care and the overlap with the social services transport budgets, for example. So the answer is probably yes, there is never any harm in getting that message across loud and clear, but no one is giving the other message. When we get our work with advisers in DWP, Jobcentres and Citizens Advice, etc, they are all telling potential claimants of DLA, "You can use this for anything. Don't be worried; don't think you have got to use it for anything." "Oh, but I don't need anyone to actually get me out of bed." But if it takes you two hours to get out of bed and then you are knackered for two hours, you might qualify, and then you can use it however you want to spend it. The message going out from advisers within and outwith Government is always that this is a benefit for you to use because you have a disability or health impairment.

**Q55 Karen Bradley:** To summarise, are you saying there is no overlap with DLA and other budgets within the NHS and social care?

**Professor Sainsbury:** It is hard to say whether there is or there is not, but people do spend their money on care, and there are care budgets elsewhere, but they are separate.

**Claudia Wood:** I personally think that because money is quite tight for most disabled people—I mean a lot of people who receive DLA are unemployed and have care needs which are not meeting eligibility criteria on the social care side—out of necessity that DLA will have to be used on the most important things to them, which is getting them out of bed, for example. That is not to say that everyone is using it for that purpose; I just think in some cases where money is tight, DLA has to go on the basics, and when you are disabled the basics are care and food.

**Sue Royston:** Our experience is it is a very efficient benefit because people are able to spend it as suits them best. Some people will use it on pain therapies they cannot get with the NHS, because they say if they cannot get rid of their pain they cannot do anything else. Other people will use it for transport. It depends on the individual circumstances, and the person is best placed to see what will help them be

more socially included and enhance their lives and enable them to take a fuller part in society. So it seems to us an incredibly useful extra costs benefit that, by allowing people to spend on what will best enhance their life, is very efficiently used.

**Professor Sainsbury:** One of the interesting findings from our piece of work, and this was not a survey so we have got no numbers here, was those people who used it effectively to keep themselves out of social care, because the money they used could allow them to stay in their home. They could give their neighbour a little treat because they came in and helped them and maybe got them out of bed when they needed it. They were using it to enable them to stay at home rather than make a call on the social services budgets. So there was a sort of overlap in the opposite direction, if you like.

**Q56 Karen Bradley:** But because local authorities have different approaches, presumably some people are using it for social care, perhaps to pay for their meals on wheels or something like that, because their local authority does not provide that free of charge. In other local authorities there would be an overlap because they are getting free meals on wheels, which they therefore do not have to pay for out of their DLA.

**Sue Royston:** I think obviously there is an overlap in the sense that DLA is taken into account for social care, so some of the DLA is actually used to pay for social care.

**Q57 Glenda Jackson:** Increasingly, local authorities are means-testing for everything at the moment, and taking things away.

**Sue Royston:** Yes.

**Q58 Debbie Abrahams:** Can I ask a slightly different question then? In those areas where there might be different eligibility criteria around social care, so we get the meals on wheels example, are we then saying there are disabled people in other areas who are less likely to get as comprehensive and as wide quality of life because of the eligibility criteria there? So it is enabling an enhanced quality of life for some people but not for others. Would you say that is fair?

**Professor Sainsbury:** I think that is the nature of local autonomy, isn't it? That would apply to so many areas of life. It depends where you live, on your local council and what they provide. No one from central Government is telling local authorities what to do, so the experience of individuals, whether they are DLA recipients or not, will be very, very different. And you are right, a good example is free meals on wheels or pay for meals on wheels. But I cannot see how that can drive DLA policy, to be honest.

**Claudia Wood:** Similarly, DLA levels are not regionally variable. So obviously what you can get for your income, regardless of where it comes from, will be different in London, when you are paying for transport, than it will be in other parts of the country, although we do have to remember about 80% of local authorities are at substantial and critical needs now. Those using DLA for the preventative, lower-level services would be the norm, I imagine.

**Q59 Chair:** From what you are saying, Professor Sainsbury, a single assessment would not work therefore between social care and DLA because they are actually assessing different things.

**Professor Sainsbury:** I think so. Clearly, there is an overlap because some people will use their DLA to pay for bits of social care if they want to, but they are doing very, very different things. This is not a care benefit. We use care as a proxy, and some people have criticised that, and that is a historical legacy too because when we amalgamated the old Attendance Allowance and Mobility Allowance we brought in care and mobility, and we stuck with them. We could have done something else and we could do something else now. The proxies are the proxies. This is not a care benefit; it is about offsetting the cost of disability.

**Q60 Glenda Jackson:** We are moving on now to the changes in the qualifying period. At the moment for DLA the qualifying period is three months. It is now going to be doubled for PIP to six months. Has anybody looked—well clearly, Sue, you have—at what the likely impacts are going to be?

**Sue Royston:** Yes, this is something we are very concerned about because obviously the two big things that Citizens Advice Bureaux (CAB) advise people about are debt and benefits. Consistently, CABs over the years have done surveys of the reasons why people get into debt, and consistently in about a quarter of cases serious illness is the most important reason, particularly when somebody has a sudden onset. Say somebody is working and earning say £400 or £500 a week, and then has a diagnosis of cancer and suddenly has to stop work. Their budget and their life is fixed at that level of income, and they suddenly find themselves dropping to SSP<sup>2</sup> levels. It is a dramatic drop in income and it is very hard to adjust. They may have a small amount of savings, but those savings very quickly go. It is not surprising that people get into financial difficulties.

We see a lot of people in financial difficulties because of this—a stroke, a serious accident. We see a lot of people that get into serious financial difficulties because they have to wait three months. Obviously, at three months, not only does the DLA kick in but also, if they live on their own, for instance, at the moment the Severe Disability Premium then kicks in as well. If they have got a partner, then the Carer's Allowance kicks in. So this makes a huge difference. We are seeing a lot of people in serious financial difficulties after three months. The idea of it stretching to six months really appals us. We are really very frightened about the results of that.

**Q61 Glenda Jackson:** Presumably, there are backdated payments after the three-month period.

**Sue Royston:** No, because to qualify for DLA you have to have had those care needs for three months, so your DLA starts at the three months. So you have three months just living on SSP basically.

**Glenda Jackson:** Right.

**Q62 Chair:** Is the answer to that, if the Government are going to go all this way of bringing in a brand

new benefit, there should be a temporary benefit that people could apply for.

**Glenda Jackson:** A bridge.

**Chair:** Because I think part of the problem is DLA is a long-term benefit and therefore you have to prove a long-term need. But if the reassessments are coming in and more frequently, and they could happen at six months, that might help to answer the point you have made: somebody who for six months or a year has very high care or mobility needs, but after that they won't at all.

**Sue Royston:** Yes, absolutely. If something could start immediately, that would be wonderful.

**Q63 Chair:** But that is not what the Government is proposing at all.

**Sue Royston:** No. One of the things that we have suggested, which we hope might be taken up, is that instead of the six months qualifying and the six months ongoing, if they want to go to a year they move to three months and nine months. That would be less good than the present system, but would at least be better.

**Q64 Chair:** Is the reason the Government has not thought of having a temporary benefit that once you have given people the money it is very difficult to take it away from them? That is why they want to prove that long-term need, because the Government is not going to be the big, bad Government taking money away from you after six months.

**Professor Fothergill:** I would not want to necessarily quibble with the notion that at the front end, when claims would first be made, the time limit of six months is going to have a detrimental impact on some people. But I think we need to keep it in perspective. The vast majority of DLA claims are long-term claims—very, very long-term claims. Of the 1.25 million who are out of work and receiving DLA, about 1 million have been receiving it for at least five years. So I do not think tinkering at the front end is going to make a very big difference to the overall numbers.

**Q65 Glenda Jackson:** But it is not the only change that is coming down the pipe, is it? We have already spoken about the kind of passporting of benefits, which is not going to happen, and how people will be taken off existing benefits for a variety of reasons. So I think we are justified in raising the possibility that this is, as Sue has said, going to cause really serious harm to people.

I have a constituent in precisely the case that Sue has quoted to us, and it is having serious implications over and above the illness she is actually suffering from, and she is going to be much, much more damaged.

**Claudia Wood:** Yes.

**Q66 Stephen Lloyd:** But also picking up on what Glenda is saying, Professor Fothergill, other than cutting costs, what is the rationale for the DWP to move it to six months?

**Professor Fothergill:** I think you would have to address that one to DWP, but I would assume they want to cut costs but also minimise administration,

<sup>2</sup> Statutory Sick Pay



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and particularly cut out what might be a very small number of very short-term claims that would be costly to administer.

**Chair:** I am going to move on because I realise we have still got some important stuff to do, particularly about the assessment criteria.

**Q67 Brandon Lewis:** I am aware that we are quite short of time. I want to ask something specific. We have had a general discussion, so I won't go too far. There is a view that it would be too complex and expensive to have an assessment in time taking account of all the extra cost. But bearing in mind what was said earlier, particularly by you, Professor Sainsbury, do you think there is or could be a way that is not too complex or too difficult to assess as part of the assessment the social environmental factors, particularly obviously in an objective way, that could be taken into account?

**Professor Sainsbury:** The short answer is anything can be taken into account. As I say, we have care and mobility proxies as a historical legacy. You asked earlier, isn't it right that we look at this benefit? I would say absolutely. But we have not had the discussion between Government and outside about what the benefits might look like in the future—a sort of blank sheet, as we have done with Universal Credit; very much, "Let's start from scratch and see what we need."

We haven't had that discussion with DLA. The reform was introduced last summer as something that was going to happen. The consultation paper itself only says, "This is a consultation paper about the assessment criteria," not about the need for reform or about the architecture of PIP. So we have not had that. I think if we did, it would at least allow us to look at, if you do want a benefit that is going to offset the cost of disability, how do we best do it? We have this historical legacy of care and mobility needs. They do not work perfectly. Could we do better? The answer is we do not know, because we have not even talked about it.

**Q68 Brandon Lewis:** You have probably answered my next question. Is there a way you can think of that you could assess these more social environmental factors in a way that does not become a huge grey area that is extremely subjective.

**Professor Sainsbury:** No, I think as soon as you add in things like that, which are very locally based, my social environmental factors are going to differ from someone across York, let alone in a different part of the country. Whether it is a good idea or not is one issue. Would it be complicated? Absolutely. But I know Claudia has got things on this.

**Q69 Stephen Lloyd:** On the 12-month issue, the DWP's current thinking is the PIP assessment will consider impacts of disability over a 12-month period. In your judgment is this likely to be a more effective and objective way of assessing fluctuating conditions? Because that has been an issue. Sue, going to you?

**Sue Royston:** I am concerned they are just using a timing thing rather than looking at the intensity of the problem as well as how often it fluctuates—having a

system that just says, "Do you have this level of disability half the time?" and if you do not, you are out of it. I think it is worrying because that does not take everything into account. We would like to see a more personalised model. I accept there are problems. Scope has done some work looking at a more personalised model that considers all the barriers and takes an overall view. We think this would deal with fluctuating conditions in a rather better way than this, which seems objective, but actually by being objective fails the Government's criteria of being personalised and looking at who has the greatest costs.

**Q70 Stephen Lloyd:** Would you agree, though, that it would provide more of an opportunity to take on board fluctuating conditions than the current system or not?

**Professor Sainsbury:** I do not think it does. DLA regulations allow time to be taken into account in making an assessment about whether the criteria are met. It is not set out in points, and it is not set out in half the time over a period of a year. But certainly all the DLA criteria are meant to take into account things like how long things are going to last, fluctuating conditions, how long it takes you to do things, etc.

I think the PIP draft regulations are an attempt to deal with fluctuating conditions, which are really very difficult to deal with, but I think it will be a nightmare for the assessors and for claimants. What evidence is going to be used over the course of a year to show I have a fluctuating condition that creates needs 51% of the time? I really do not know how assessors are going to do it, and I do not know what I have to do as a claimant to meet this particular criteria.

**Q71 Stephen Lloyd:** Have you seen the more personalised Scope proposals that Sue is alluding to?

**Professor Sainsbury:** I have seen them, and I cannot bring them to mind.

**Q72 Stephen Lloyd:** Do you think they could be a bit better? Because the reality is, as Roy has said, measuring fluctuating conditions, whether it is MS, mental health or what-have-you, is fantastically difficult. It is something I think is incredibly important. Other colleagues and I on the Work and Pensions Committee have been drilling away at the Government on this. It is quite difficult to come up with something that is a better measurement than I have seen than a 12-month period, even though I accept what you are saying, Professor, about how you show proof over a 12-month period. So what ideas would you have?

**Professor Sainsbury:** Do not forget, we are only talking about this because we have proxies of care and mobility. Fluctuating conditions are particularly relevant for the amount of help you need, certainly if you have good and bad days. It is only because we are stuck with these care and mobility proxies that we are actually having this conversation. If we went down your route and had a wider look at how we should be assessing costs of disability, we might come up with something completely different that would take a different approach to fluctuating conditions or do away with their relevance altogether.

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**Claudia Wood:** I think we may not need to get hung up on that too much if we think your level of need or the complexity of your condition does not necessarily drive your disability costs. Having your own transport, suitably adapted housing and informal care networks drive a lot of disability costs. If we were to move to PIP, it would be really good to see that you would have to report changes in your circumstances to include, "I have been bereaved; I have been evicted and I now live in a top floor flat, which is completely unsuitable for my needs." But it will actually be, "Well, my condition has changed," which does not necessarily mean your life is more or less expensive. I think that would be an interesting one to do.

**Q73 Stephen Lloyd:** Sue, anything else?

**Sue Royston:** The Scope model basically uses the social care model, and the assessment would be similar to how social care is assessed.

**Q74 Stephen Lloyd:** Moving on to aids and appliances, which is a challenging one. They can be incredibly relevant to certain disabilities. The DWP have said it will deal with the issue sensitively and proportionately. In your view, is there a danger taking account of aids and appliances in the PIP assessment could discourage people from using them or not?

**Sue Royston:** It strikes us that DWP are slightly trying to have their cake and eat it, in that they are using the social care model to take money away from people in terms of aids and appliances but not using it where it increases people's costs. We are concerned about the use of aids and appliances if it means that people are not then going to be seen as having those needs because using aids and appliances is often a very good proxy for extra costs. If somebody is in a power-assisted wheelchair, that makes them very independent but there are extra costs.

**Q75 Chair:** They need to buy the power-assisted wheelchair though. Has there been a softening of the DWP? It was really quite hard in the original consultation around this, but in drawing up the criteria has that softened a bit? Have they realised there are expenses attached to it?

**Claudia Wood:** I do think they recognise they would have built in an almost counter-intuitive feedback loop, which is, "Use your DLA or PIP to buy an aid and appliance"; you are therefore more independent, therefore you lose your PIP.

**Professor Sainsbury:** Therefore you lose your appliance.

**Claudia Wood:** Yes. I think we do have to recognise that aids and appliances generate their own costs. What you are really doing is transferring your costs. Before you had an aid and appliance you had to get someone to help you with it, and now you have one you have to charge your battery.

**Q76 Chair:** This takes us back to the questions that Karen was asking about the double accounting. The assumption was that the aids and appliances were provided free by either the health service or social care, when everybody with a disability knows that what you get free is often not what you require, or

indeed not necessarily adequate to give you independence. Do you think that is why that came in in the first place? Perhaps on closer examination the Government is beginning to realise the overlapping expenditure they thought was there is not necessarily there.

**Sue Royston:** Yes, I think that probably has been an issue.

**Chair:** Okay, we had better move on.

**Q77 Andrew Bingham:** Given the timetable for the introduction of the assessment, do you think the DWP have made enough progress to finalise an assessment, or should they have made more?

**Sue Royston:** We are concerned that, although we have the draft regulations about what the descriptors are going to be, we have not actually got a points level. We still have no idea who is going to qualify, because unless we know what the points thresholds are going to be we have no idea.

**Professor Sainsbury:** My understanding from DWP's submission to this Committee is they seemed to be engaged in testing over the summer. I have not seen anything in the public domain.

**Q78 Chair:** They certainly recruited people to take part in the test, but I do not think we have had any feedback. We might get that from officials.

**Professor Sainsbury:** I will just read this from their submission: "The assessment testing will be complete by mid-September." That was a month ago.

**Chair:** All right, so that is a question for us to ask.

**Professor Ray Sainsbury:** You might want to pursue that with DWP. If there is anything coming out of that, we would all be extremely interested in seeing what they think. We need to know where the points are going, how many, the thresholds, and the amounts of benefit.

**Q79 Andrew Bingham:** The DWP plan to use a commercial organisation to do the assessment, as they have for the WCA. Is that an inevitability and do you think there are some other commercial organisations, or is it just Atos and nobody else?

**Sue Royston:** We have been saying for a considerable number of years there is a systemic problem with face-to-face assessments. To be honest, there was a problem with face-to-face assessments when they were done within DWP as well.

**Q80 Andrew Bingham:** Such as? When you say a problem, can you give an example?

**Sue Royston:** Well our advisers have repeatedly reported that the accuracy of the reports produced in these assessments is not good, but there are two parts to an assessment report. The first part is meant to be a straightforward account of the interview the client has with the assessor and record what the client says. Then the second part is the healthcare professional using their own—

**Q81 Andrew Bingham:** Interpretation of it.

**Sue Royston:** Judgment, yes. Our advisers have repeatedly reported that first part is inaccurate. When we have presented evidence, Atos or DWP have

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always said, “Yes, of course there are some errors; it is a tiny proportion.” We saw 200,000 queries last year about ESA. We see a huge throughput through Bureaux. Our advisers are telling us it is a systemic problem. Because Atos have a review, we have repeatedly requested they send a copy of the report when they do customer surveys, so that when the client is saying whether the doctor listened to them, it is an informed response. They can actually look at what the doctor has recorded they said.

We got nowhere with that request, so we have just done an indicative study where we looked at the accuracy of the reports. In order to make sure that we were not looking at clients who had had a poor assessment already we asked clients to take part in our survey before they had been to an assessment, and then the adviser spent the year following them through the process, and then asking for the report, and then going through the report with them and looking at the accuracy.

**Q82 Andrew Bingham:** I am sorry to interrupt you. Are these inaccuracies mistakes or are they assessments that people did not like? They were expecting one thing and got another, and they were more concerned about the result than a distinct factual inaccuracy.

**Sue Royston:** It was not about the result. In fact, out of 16 of the 37 reports we did, the adviser and the client felt they were seriously inaccurate. In nine of those 16, the person had actually been awarded ESA, so they would not have even known had they not seen the report.

**Andrew Bingham:** Sorry to interrupt you again, but the other 19 were fine?

**Sue Royston:** Sorry, no. We had a medium level and a good level. There were 11 that were absolutely fine—reports where there might have been one or two small mistakes, but they would not have made a difference.

**Andrew Bingham:** Tolerable, yes.

**Q83 Stephen Lloyd:** When were these done? Was it prior Harrington changes or post?

**Sue Royston:** Well, it would be done over the period, so some were prior and some were post.

**Professor Sainsbury:** Is this the DLA?

**Sue Royston:** This is for ESA, but we are looking at face-to-face assessments and the accuracy of them.

**Q84 Stephen Lloyd:** That is a shockingly high percentage. You are talking in the region of 35% inaccurate factual reports.

**Andrew Bingham:** But this was on a sample of 37.

**Sue Royston:** Yes.

**Andrew Bingham:** Not a big sample.

**Q85 Stephen Lloyd:** It is a tiny sample, I agree, but that is quite shocking.

**Sue Royston:** Statistically for those numbers if we had an approximately random sample, we could be 95% confident that, based on the criteria we used, and obviously it is the customer’s reaction to this report, the accuracy is between 27% and 53%. So we are just looking at a ballpark figure, but we used it as an indicative study to say, “This is evidence there needs

to be independent research on the accuracy of these reports.” We would like to see an independent study where the customer gets the copy of the report and reports on how well they are recorded. In some cases, there were really dreadful levels of recording of what the client had said.

We would also like to see some independent survey of the inconsistencies, because there were a number of inconsistencies. For instance, one healthcare professional recorded the person had epileptic seizures once a week, and then awarded the descriptor of once a month. The decision maker did not even notice that, and awarded the points for once a month. So we also looked at the inconsistencies.

**Andrew Bingham:** I would not contest you for that. My only observation on that would be 37 is not a huge number to do a sample on. I am not contesting your findings—I would not do that—but I think if you want to get a real body of evidence you have to get more than that.

**Q86 Chair:** To move it on, we are very well aware of the flaws of the ESA and the WCA, and we have taken evidence on that, so as a Committee we are very well aware of that. I think part of the suspicion amongst people reporting to us is they think that same technique will be used for PIP, and therefore they are particularly worried. So I suppose the question Andrew has asked is whether there is another commercial organisation other than Atos that can do these kinds of assessments, and do they have to be done in the way they are being done? You can still have the criteria; you can still apply it; but are there other companies anywhere in the UK or the world that do this kind of assessment, but much more sensitively and more accurately than what you have experienced from Atos?

**Sue Royston:** I do not know, but we are saying there is a problem with the way they are doing it in the 40 minutes.

**Andrew Bingham:** Yes, we have got that.

**Chair:** No, we understand that.

**Q87 Andrew Bingham:** I think we have got that. The question is, is it inevitable we have to do it the same way or is there another way?

**Professor Sainsbury:** There is one simple change you could make to this whole assessment procedure and that is to have a co-produced factual report. It is not left to the assessor, whether it is a medic or anyone else from Atos or anyone else, writing down what I have said and then doing this factual and then the interpretative report. Instead they say, “This is what I am writing down about you, Mr Sainsbury. I put down you can do this, you can do that.” “No, I did not say that.” “Oh, right, well...” and then you both sign that and you have got an agreed factual statement.

Now the interpretation by the assessor can be, “I have looked at all this; I have looked at the criteria; I think this.” It is what happens with the advisors in Jobcentre Plus. They will sit down with a jobseeker and say, “I am putting down this; I am putting down this, because that is on the action plan.”

**Q88 Chair:** And they show them the screen.

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**Professor Sainsbury:** They show the result, “This is the action plan,” and they both sign up to it.

**Q89 Chair:** If you phone the Tax Credit helpline, they automatically tape your call, which you can then recover if you have any dispute. Would there be any advantage in doing that kind of audio taping, or what you just suggested?

**Professor Sainsbury:** That is belt and braces.

**Q90 Andrew Bingham:** Sorry to stop you finishing, but if you start recording it, it almost has an air of “anything you say will be taken down,” and you get the two tapes, and it all looks a bit like *The Bill*, doesn’t it?

**Sue Royston:** They are actually piloting recording it as a result of a recommendation by Professor Harrington.

**Q91 Andrew Bingham:** It could just give the wrong impression; that would be my concern with that.

**Sue Royston:** Yes, and you can get a copy of the report.

**Andrew Bingham:** Not by default

**Claudia Wood:** Professor Sainsbury’s suggestion would be far more low-tech but far more successful. Have it co-produced by essentially sitting down next to the person rather than opposite on the table. Not only does the person see what is going on, but there is less risk of tribunal and that sort of thing later. If you go through the process with someone and they buy into it and see the outcome, even if the outcome is not what they want, the chances of them complaining are much lower because they have actually been included in that process. They understand why that decision has been made as opposed to the more opaque system of someone putting something on a computer and you get the result without knowing why.

**Professor Sainsbury:** Because the criticisms are not always that he or she got it wrong, but, “I said all that stuff about going shopping and it is not there; it has been ignored.” So again, a co-produced report would give the claimant the chance to say, “No, I want to put down that bit about how difficult it is get to the shops.”

**Q92 Andrew Bingham:** Okay, I am just trying to move us along a bit because I am conscious of the time. The Welfare Reform Bill envisages an independent review of the PIP assessment within three years. Do you think three years is too long, too short or about right?

**Professor Sainsbury:** I suppose it is like a Harrington approach to it—to have a rolling review of these assessment criteria. Three years, you say?

**Andrew Bingham:** Yes, it is three years.

**Professor Sainsbury:** It sounds a long time to me.

**Andrew Bingham:** Right, that is fine.

**Q93 Andrew Bingham:** Without wishing to put words in your mouth, would you support an annual review, say, for the first few years while it settles down?

**Professor Sainsbury:** Absolutely, for the first few years, not for ever, because it is going to be so different. As Steve said about the WCA testing, the forecasts were very wrong. They said some 10% were going to lose IB but it is 30%. I think we need to make sure this test, whatever it will look like, is on the right track early on. So I think annual to start with would be very sensible.

**Andrew Bingham:** Do you want me to carry on?

**Chair:** I think Stephen has a question on this, and then you can carry on.

**Q94 Stephen Lloyd:** I was going to go onto the media one, because it is something that has come up an awful lot—the reporting in the media around both DLA and PIP, and generally the whole changes around disability. Because we have four of you here, I would value your thoughts. The Select Committee and individuals on the Select Committee and in the Chamber have been quite robust with the Ministers, saying, “Change the language. It is not helpful,” *etc.* The Ministers for quite a few months now said they have changed the language. Obviously, they do not have any power over the *Daily Mail*, God bless it, but despite that there is still a view out there that the language is very negative. However, the Government are saying, “What can we do? We have changed; Ministers are not using the sort of language that they may have been using seven or eight months ago. It is not our fault, gov.” What is your take on that, bearing in mind we do have a “free press” who obviously have a particular line and agenda whenever they are talking about disability and benefits. So what is your take?

**Sue Royston:** Just very recently there has been an article about naughty children syndrome and getting a higher rate of mobility if a child is naughty, which was completely inaccurate. We are very concerned. Disabled people are repeatedly telling us how worried and concerned they are about the situation and find it very distressing when they have a serious impairment to have this continuous assault in the media.

One area we would be particularly concerned about is, in the same way as the reduction in numbers of ESA was played in the media, there is clearly going to be a reduction in the number of disability benefits, and we are very concerned about how that is going to be portrayed in the media. We would like to see that very carefully done.

**Q95 Stephen Lloyd:** I agree. Whether I like it or not, I have got no control over *The Mail*, *The Sun*, *The Express* whatever on this issue. What we are very careful about, though, and have been very specific with the Ministers, is they must change their language. The DWP must change the way they put out press releases, so they are more objective and, if anything, glass half full. This is trying to get people back into work, *etc.*, as opposed to “benefit scroungers”. The Ministers are insistent they have changed their language over the last X months. I am interested in from your academic and CAB background, is whether you think the DWP and the Ministers have changed and it is the usual suspects just writing the way they always do about benefits, or have the DWP not taken it on board?

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**Professor Fothergill:** I was not going to comment specifically on the use of language, but I was going to say that where I think the Government has a very fair point that it does need to make is that DLA has been subject to remarkably little scrutiny over the years, given the extraordinarily large numbers of people who claim it and the very large amounts of public money that fund this benefit—£12 billion a year. Normally, there would be an absolute raft of studies and investigations into that sort of level of spending. So there is a fair point there. But I think the whole issue is never characterised very accurately. This applies not only to the Government but also the way the media seem to handle it, and that is to characterise the issue as being about individuals with acutely high levels of disability, electric-wheelchair users, for example. It is often quite wrong. We are talking about a much wider swathe of the population here. I think that needs to be made very clear.

The other thing that tends to be overlooked by virtually everyone is that this is about particular places. This is a benefit and a policy change that will overwhelmingly impact on certain parts of the country, but virtually leave the people in other parts of the country unaffected. They will not be completely unaffected, but this has a distinct geographical policy impact, and I do not think anybody has really addressed that very centrally at all.

**Claudia Wood:** In terms of the language, I think one of the common errors that the press make around ESA, which I am assuming will be applied similarly when the assessments come out, is they conflate new claimants with existing claimants. So they will say 800,000 people have been fiddling the system. Actually, that is the number of new claimants who have failed the new test, so they have not fiddled—they have not claimed anything they were not supposed to get—they just failed the new test. When that sort of press release comes out with the DWP, and these are recent and objective press releases, the quote from the Minister that comes out is, “This is why we must reform the system,” as if there is something broken with the old system, which is why new claimants are failing the new test. It is that conflation that encourages this idea of fiddling when all it really is is the Government has decided rightly or wrongly to move the goalposts of the assessment. At the Conservative Party Conference a couple of weeks ago, in Iain Duncan Smith’s speech there was a clear linkage between a long-term benefits claimants, IB claimants, and moral problems and rioters. In the same breath as talking about long-term benefits claimants, he talked about Baby P’s parents. The idea that somehow you have moral delinquency as a result of being on benefits for a long time potentially is true for a very, very small minority, but to make it into a social problem and create a moral panic I do not think is helpful.

**Q96 Chair:** The question of the figures for ESA is quite an interesting one. I tried to find out what the drop-out rate was for IB. Unfortunately, the Department did not keep those figures, so there are no comparable figures for new IB claimants and new ESA claimants. In fact, the profile might have been

identical, but we do not know. For IB you would have to add the support and the WRAG (work related activity groups) groups together, but it could be quite similar. Would they be able to do the same with DLA, or do the figures exist for the numbers who are not awarded DLA? I think somewhere in our briefings it said 50% of those who apply are not awarded, which would suggest it is perhaps quite a tough test to get. So if the new claimant figures come out as 50%, then actually it is no different from existing DLA. But do those historical figures exist to make those comparisons?

**Professor Sainsbury:** There are certainly figures on numbers of DLA claims disallowed. They exist, and I have got them here actually somewhere in this pile. But to understand and get a better picture of what is happening, you would also need to feed into those the numbers that appeal after that and are successful. We are not just talking about tribunals.

**Q97 Chair:** And of course the new claimant figures are pre-appeal as well.

**Professor Sainsbury:** Exactly, so I think the figures are only about half of DLA original new claims succeed, but quite a lot of those go on and ask for reconsideration. That is a middle-tier appeal, if you see what I mean, before the tribunal, and a lot get overturned there. Then the success rate of cases going to tribunals is very, very high—somewhere in the region of 40%. So, ultimately, much more than 50% get their award. Some people indicated there is something wrong—that this is people making speculative claims.

**Q98 Stephen Lloyd:** Being realistic, is it possible that DWP or the Government would ever be able to change the language approach that certain sections of the media use?

**Professor Sainsbury:** I was very intrigued by your question, because I have not noticed any change in the language.

**Q99 Stephen Lloyd:** I have, to be fair. I mean other than the Iain Duncan Smith thing; I was a bit miffed by that.

**Professor Sainsbury:** You have been watching and I have not, but I think it is a very difficult one for the Government to sell because this is a policy that is going to save money. It is designed to save money. This is one of the rare policy changes where there are no winners. There are absolutely no winners; there are just losers—losers from people who are at a low level of disability who will not get PIP in the future, and for existing DLA claimants, who are going to be reassessed on to PIP. There are no winners, and this is a very, very hard one to sell. So the language we see in the documents is about fairness and responsibility and focus on very disabled people, but no one is fooled that this is a policy whose effect, in these austere times you can see why, is effectively to save public money.

**Claudia Wood:** I think some of the quotes at the bottom of the press releases, whilst they no longer say “scroungers and fiddlers,” still often have a dichotomy between taxpayer and disabled person, which you see

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quite regularly as if they are mutually exclusive groups. You will often see, “We have tightened up the goalposts.” In the appropriate ministerial quote that could be, “We have tightened this up because there is an austerity package in place and we have to have a narrower perception of what we mean by disability supported by the state.” But what they say is, “This is why we have to get rid of people who have been on benefits for years,” willingly conflating long-term benefits claims with new applications, and I think that is still disingenuous.

**Q100 Chair:** I think it is that conflating of figures we would be particularly concerned about as a Committee. One final question: is there a case for automatic entitlement to the new PIP for either particular conditions or people who have been assessed to death everywhere else and it is clear they have a severe disability—so some kind of either online assessment or a triage system so they do not have to go through the face-to-face interview? I am thinking here particularly of when the Benefits Integrity Project was introduced and the more severely disabled were getting visits or called into Jobcentres, or whatever they were called at the time, to go through interviews. Is there a case for automatic entitlement?

**Sue Royston:** I think there is a case for and against. We would like to see at least a minimum level of automatic entitlement, because there are some groups where it is quite clear they are going to be entitled to some. I think it would certainly help with take-up. I think part of the problem with take-up, going back to the beginning, is it is a complex benefit. If a doctor does not feel confident that you absolutely will get the benefit, they often will not recommend it. Therefore, if you could say that for certain groups of people there was an automatic entitlement to at least the lower level, that would be very helpful.

We can see a case for many groups putting an exact level on because we do not want to go too far down the route of the medical model, so we would like to see it more personalised beyond that.

**Q101 Chair:** But if someone has cerebral palsy, has no control over his bodily functions and lives life in a wheelchair, why do they need to be assessed?

**Sue Royston:** Yes, absolutely. We certainly see a case for not having face-to-face assessments in a lot of cases, even if there is not automatic entitlement.

**Q102 Karen Bradley:** Isn't that the case with the Work Capability Assessment? If you reach a certain level of points on the completion of the form, then there is no face-to-face assessment. It is automatic.

**Sue Royston:** Yes, you can if you are in the support group.

**Q103 Karen Bradley:** So you would hope they might have something like that.

**Sue Royston:** Yes.

**Chair:** Okay, I am going to have to bring this to a close, because the House is now sitting and we always overrun. I think that has something to do with me and my chairmanship. Thank you very much for coming along this morning. I know there were lots of other things you wanted to say, but I think we have a good flavour for us to now go and interrogate some of our other witnesses with these aspects as we continue this inquiry. Interestingly, we are going off to Neath in South Wales, which has one of the highest level of DLA claimants anywhere in the UK, which we have discovered, I think, as a result of your research, Professor Fothergill. So that will give us a good insight into some of the things you have said. Thank you very much for coming this morning.

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## Wednesday 23 November 2011

Members present:

Dame Anne Begg, in the Chair

Debbie Abrahams  
Harriett Baldwin  
Andrew Bingham  
Karen Bradley

Sheila Gilmore  
Oliver Heald  
Glenda Jackson

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### Examination of Witnesses

*Witnesses:* **Amanda Batten**, Director of External Affairs, National Autistic Society, **Neil Coyle**, Director of Policy, Disability Alliance, **Paul Farmer**, Chief Executive, Mind, **Geoff Fimister**, Campaigns Officer, RNIB, and **Eugene Grant**, Public Policy Officer, Scope, gave evidence.

**Q104 Chair:** I welcome you to the second formal evidence session of our inquiry into the change from Disability Living Allowance (DLA) to Personal Independence Payment (PIP). I apologise for the numbers on our side being a bit thin. The reason is either fog or leaves on the line. I am sure that my colleagues will turn up soon. Could you briefly introduce yourselves and the organisations you represent? We'll start with Amanda.

**Amanda Batten:** My name is Amanda Batten. I'm director of external affairs at the National Autistic Society.

**Chair:** Although there are microphones in front of you, they are for the sound recording. They don't amplify the sound, so please speak up nice and loud.

**Paul Farmer:** I'm Paul Farmer, Chief Executive of the mental health charity Mind.

**Eugene Grant:** I'm Eugene Grant, Public Policy Adviser at Scope.

**Geoff Fimister:** I'm Geoff Fimister, policy adviser to the Royal National Institute of Blind People (RNIB).

**Neil Coyle:** I'm Neil Coyle, Director of Policy at Disability Alliance and Director of Policy and campaigns for Disability Rights UK, which opens its doors next year and is made up of Disability Alliance, the National Centre for Independent Living and Radar.

**Q105 Chair:** I think I followed that. I'm sorry you're all a bit crushed on the top table. There's more room in Portcullis House, but unfortunately we are in this room this morning.

One of the main criticisms of the existing DLA criteria is that they are far too heavily weighted towards people with physical disabilities and impairments and do not adequately reflect the impacts of sensory and intellectual impairment. We had a very well attended public meeting in South Wales yesterday. It was so big that we had to change the venue at the last minute. The local autistic society had been very active in getting its members there, so the questions were very much about the effects of the new PIP on autistic people in particular. Is what I've referred to one of the main criticisms of the existing system?

**Amanda Batten:** Yes, the National Autistic Society would certainly concur with that. The current DLA application and assessment process is very focused on physical difficulties. That makes it quite difficult for people with conditions such as autism to fill in the

form. In practice, people tend to rely on the "Any other information" box at the end. That's once they've got through the 50 pages that they can't quite relate to. The disadvantage of that is that sometimes people feel like the benefit is not for them, and perhaps are discouraged from applying, or they need help and support to fill in the form.

An example of that would be the mobility section. It rightly talks about how far you can physically walk, which is obviously appropriate for some groups, but it would not give you an opportunity to talk about the challenges you might face with mobility if, for example, you have difficulties planning and following a journey. Some people with autism might find the environments in public transport totally overwhelming—very difficult to navigate; might not be able to cope with changes in routine; or have no concept of safety or hazards. So they may face barriers in terms of mobility but it is quite hard to capture that in the current system.

**Neil Coyle:** If I can just add to that: the criticism there is of the process for entering the benefit. The criticism is not of the benefit in terms of what it allows you to achieve once you have accessed DLA, in the way it is paid, in the fact that it is paid to people in work or out of work. Those kinds of issues mean it is very flexible. It is the process for getting in that was the focus of the quest for reform in the past. Most of us have sat together and asked governments of different times to reform DLA in the past—in particular focused on the process for entry, and the bureaucracy involved in trying to get on to DLA. It should probably be noted that about one in eight of the people who will be going through the new assessment process for PIP are those with learning difficulties.

**Q106 Chair:** Okay. We will be picking up later on whether what is being proposed in the second draft of the criteria in the PIP will answer some of those questions, or not. Just at the moment I am really trying to codify—because the Government say that DLA is poorly understood and poorly accessed by certain groups of people. I am just trying to get that critique of the existing DLA at the moment.

**Geoff Fimister:** Throughout the lengthy consultative process over DLA and PIP, we have repeatedly pressed the issues around communication and orientation and the need to address those dimensions that are so important to people with sensory

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impairments. We feel we are beginning to get that argument across now; the debate seems to be shifting to an encouraging extent.

Could I also say that I spoke to my colleagues in Neath last night, to see how it went, and I think people do not expect Parliament to come to them. I think your visit was very positively received, from the comments that I got back.

**Chair:** We are glad to hear it, because the last speaker at the meeting was less than complimentary, but it did mean as a result that lots of people said, “No, thank you, we are really glad you did come.” It was nice to do it, and we are glad we did it.

**Eugene Grant:** I think one of the things with the current DLA process is that it is very complex and arduous to complete, which is what some of my colleagues were saying; but also it is very deficit model-focused—it focuses very much on what somebody cannot do, which is particularly arduous to fill out. More than that, it also centres specifically on impairment, and what someone cannot do as a result of their impairment, rather than the barriers that society throws at them as a disabled person. I think that is a real shortcoming of the current process.

**Q107 Chair:** Okay. I will come back to you on whether the new process makes that any better. Paul, I think you want to say something briefly.

**Paul Farmer:** Building on your question about those groups who have historically found it relatively difficult to claim DLA—people with mental health problems I think constitute only around 17% of the total number of people who claim DLA at the moment, which feels disproportionately low—like Amanda, many people tell us about the challenges and difficulties of completing the form and being able to articulate effectively some of the challenges.

Equally, people who have been able to overcome that hurdle tell us about what a really very progressive benefit it is for them. For people who are in work it is helping them to stay in work. For people who are out of work but looking for work it is giving them that additional support to be able to do that effectively. For people who are unwell as a result of their mental health problems, they are telling us that it is preventing them from relapsing and potentially high-cost stays in hospital. The very flexible nature of the benefit makes it quite a progressive benefit for people. But on the entry system I agree with colleagues. It is extremely difficult for people to get in at the moment.

**Q108 Chair:** There will be questions coming up about the widening of the criteria, so I want to stay clear of that, but can I ask you a question we asked of our first set of witnesses? You have made criticisms of DLA. Did it require the introduction of a new benefit to sort out those criticisms or would it have been possible to reform DLA as a benefit as it stood? All of you have talked about the importance of it as a benefit once it is in receipt, but would it have been possible to change or reform the gateway, or find other means of improving the operation of the gateway on to DLA, and perhaps to check that people would still qualify for the benefit?

**Geoff Fimister:** Looking to improve DLA and all the issues that are being discussed could have been approached within the context of DLA itself. I don’t think there was a necessity to create a new benefit in that sense. We have simply taken it that the creation of a new benefit was a vehicle for introducing significant spending reductions. I really don’t see why it was necessary in terms of improving the benefit.

**Q109 Chair:** But Neil, your organisation has a website where you have a list of all the relevant DLA case law and it runs to 57 pages. Isn’t that the problem? Because it has been going for a long time, the case law has built up; it has got more and more confusing and therefore a fresh start on a new benefit would be useful.

**Neil Coyle:** If the Government had wanted to say that it was perhaps too easy to access as it currently stood, or that they wanted to make a significant reduction and to change the levels of payment—it was all possible. The Government could have acted to overrule some of those 57 pages—I didn’t realise it was that long—of case law. The Government have the power to do that. As Geoff has mentioned, instead of being completely frank about the Government agenda, it feels to many disabled people and disability organisations that the introduction of a new benefit, at considerable cost, is designed to mask a reduction rather than genuinely to deliver an improvement that would change all of that case law.

**Amanda Batten:** Can I just add that we were generally open as to whether DLA could have been reformed or whether a new benefit in principle was preferable. It is certainly the case that DWP has looked at and revised the existing child DLA form and has been doing some work on that, so there have been some improvements, which, potentially, could have been an alternative avenue for progressing.

**Q110 Chair:** My last question is around the perception of DLA. One of the criticisms that the Government have is that the perception among many DLA claimants is that it is an out-of-work benefit; it is not an in-work benefit. Part of the reason why we went to Port Talbot in South Wales is that it is the area with the highest proportion in the country of working age people who claim DLA. It is no coincidence that it is also an area of de-industrialisation and high unemployment. How widespread is that misperception with regard to DLA? Do you find that from members of your organisations?

**Paul Farmer:** Like all benefits, I suppose that this benefit is often misunderstood and often very hidden. Lots of people don’t know about DLA in the same way that a lot of people don’t know about Access to Work as a support mechanism for disabled people in work. Potentially, it is a tool to enable people to stay in work. Interestingly, I had a message just this morning from somebody who knew I was coming to this Committee and who has a mental health problem. They said, “I, for one, would not be able to go to work if I do not continue to get my mobility DLA. This would worsen my mental health and would leave me isolated and feeling worthless. I would feel that I am not contributing to the tax system or to society.” There



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are clearly people who do understand that DLA is an in-work benefit as well as an out-of-work benefit. In wider terms, I don't think the public understand that. The recent media coverage certainly suggests that there is not a particularly good understanding of it in the media.

**Q111 Chair:** So the proportion of people who qualify for DLA but are not claiming it are likely to be the ones in work, is what you are saying. The ones out of work are looking to maximise their income and therefore know about DLA, because they will have gone through Welfare Rights or Jobcentre Plus, which might have suggested it, but people in work do not get it. Do we know whether, if the DLA criteria are tightened, people presently in work who receive DLA are likely to fall out of work if they no longer qualify? Can you quantify that at all?

**Neil Coyle:** In the survey that Disability Alliance ran for a number of organisations alongside the Government consultation, more than half—I think it was 54%, off the top of my head—of those currently in work and receiving DLA said that without DLA or with a reduction in DLA, working the number of hours that they worked, or working altogether, would not be possible.

There is another side as well, which is about circumstances changing and DWP requiring a review based on someone going into work. There is a misunderstanding on the officials' side which has led to a question mark being put over somebody's need for DLA on entering work. Of course, being in work can have higher costs for disabled people: more transport, for example. That misunderstanding and misperception works two ways, but there is a real risk that people could be less likely and less able to work without the support that DLA provides. In particular, people in work told us it was due to transport costs.

**Q112 Chair:** But you will have heard people say, as I certainly have, "Oh, I can't take the job, because I'll lose my DLA." No matter how much they are advised that that is not necessarily the case, that perception is still very strong among people.

**Geoff Fimister:** Yes, I think that's probably true. We have undertaken research, with both Attendance Allowance and DLA, into how blind and partially sighted people actually spend it. The DLA research we did in association with Action for Blind People. Some of the most powerful case examples we got were from people who were in work. They were very articulate about how important it was to them when paying for assistive technology, travel and so forth. DLA can be a powerful reinforcement to people's ability to take up and remain in work. Although we cannot quantify it, I am quite sure you're right that there is a misconception among many people that it is an out-of-work benefit. What that suggests to us is that, as with many benefits, there is a very strong case for high-profile publicity, whether it is called DLA, PIP or whatever. We hope that as the benefit develops, that will be part of the Government's agenda.

**Q113 Chair:** I think it's easy for people to understand, if you are sensory impaired or have a

physical disability, that DLA is clearly an advantage if you are in work, because of the things you need to buy in order to access work, including Access to Work itself. But what about people with mental health problems? Is that not the group with the biggest fear of losing their DLA if they go into work? Is that different from people with sensory impairment and physical disability?

**Paul Farmer:** Because the benefit is not always that well understood, there is always a potential for that fear, but the same issues apply about clear communication and clear messages for people who are currently experiencing it. Significant numbers of people with mental health problems who are currently on Incapacity Benefit will be reassessed under the WCA<sup>1</sup>. There is an opportunity to communicate effectively with people about what is and isn't a part of those processes. One of our concerns about how this particular piece of work is being looked at is that it is often done without that broader context.

As I said, many people are currently going through the WCA, and many people are facing challenges as a result of other cuts in local authorities and other places. We know that this is a very unusual benefit in many ways, precisely because of its very personalised element, yet it is very misunderstood. We really want to encourage people with mental health problems—we certainly use all our channels to encourage them—to understand that this is a benefit which you don't lose if you find a job. That is a very important message. We know that people can be fearful of both the financial and the human costs of taking that step, but we know that among disabled groups, people with mental health problems have an extremely high want-to-work rate and, unfortunately, an extremely low in-work rate.

There is a lot of support we can usefully give. I would guess, for instance, that Work Programme providers are not telling people that their DLA is not necessarily going to be affected. I would guess community psychiatric nurses are probably not telling people with mental health problems that their DLA is not affected. It appears that it is not particularly well understood. There is certainly a need for a far greater widening of understanding about what this benefit is but also what it is not.

**Q114 Harriett Baldwin:** In that context, have you tested the change of the name from Disability Living Allowance to Personal Independence Payment on any of your user groups? Does it better convey what the benefit is for?

**Paul Farmer:** Interestingly, someone said to me yesterday that they were concerned that losing the word related to "disabled" would be a problem, because it does clearly identify who it is for. However, I don't think we have a particularly strong view about that. What is more important is what it contains and how it is communicated.

**Geoff Fimister:** We have not tested that out. I know it has arisen in the debate on the Welfare Reform Bill in the House of Lords. It has been criticised as a potentially ambiguous name—Personal Independence Payment.

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<sup>1</sup> Work Capability Assessment

**Q115 Harriett Baldwin:** The new name?

**Geoff Fimister:** The new name, because it does not mention disability. So I suppose that is a good point.

**Neil Coyle:** And it does link to the social care language of personal budgets. Personal Independence Payments and personal budgets: there is a risk of more confusion from the new name than under the former name. I am happy to do some research on this, but our members—365 local and national organisations across the country—would probably support “disability living costs allowance”, which I believe is Baroness Campbell’s suggestion.

**Q116 Harriett Baldwin:** Can you say that again?

**Neil Coyle:** Disability living costs allowance, or disability living costs budget—something along those lines.

**Q117 Chair:** What does that work out as an acronym? Nothing rude.

**Eugene Grant:** I think I draw on Paul’s point that we are not wedded to the name personal independence payment, but much more important than the name itself are the content, how it is delivered and how well it recognises the barriers people face.

**Q118 Harriett Baldwin:** On a show of hands, who would prefer to keep the name the same?

**Geoff Fimister:** I think disability living costs allowance is good; I like that.

**Neil Coyle:** I think the reason “costs” was chosen by Baroness Campbell was because DLA was introduced to help with the high cost of living. It seemed to be missed in some of the discussion of the change that DLA was about the high cost of living, and so people were routinely experiencing high costs. To have something focused on costs would probably get significant support.

**Chair:** Keep that thought in mind. At the end when we come to look at how well the new benefit is fulfilling what you want it to do, that is maybe something we need to explore further. Glenda, I think you want to come in quickly.

**Q119 Glenda Jackson:** Actually, it was in relation to something that Paul said before we got on to the change of name, which is part of something that has been presented to the Committee before.

You referred to psychiatric nurses, for example. It seems that there is confusion—and you are presenting a picture that there is major confusion around—about who can claim and maintain DLA. There are so many other areas of the state, which on the surface have no contribution to make here. This is a point we have all been banging on about for some time. These are the organs of state that should be made aware that they have responsibility in the area. The obvious one is health; the other is social services—very often they don’t know. Local authorities are very patchy in this area.

Am I right in presenting this rather bleak picture? Do you think there should be a requirement on central Government to join this up across all the organs of state, so that everybody knows they have responsibility in this area?

**Paul Farmer:** I completely agree with that. About 18 months ago, I co-authored a report with Rachel Perkins and Paul Litchfield for the DWP, entitled *Realising Ambitions*. One of the strongest findings was the lack of join-up in terms of the messages people were receiving. People do not live in departmental Government silos; they live in the real world. In that real world, people told us that one week somebody would be telling them that they will never work again, but the next week they would be called for a reassessment of their ability to work. There are huge benefits—and huge savings, to be honest—to come from creating a more joined-up approach. At the heart of that is information, in terms of people’s understanding and knowledge, but it is also an understanding of the individual’s broader experiences. I think it is very important that this particular review of Disability Living Allowance is seen in that wider context. It has a lot of potential to be an exemplar of a personalised service that is well promoted and enables people to be more independent in their living and in fact to become less reliant on the state. It is dependent, however, on people who are part of the statutory services informing that individual about their rights and their potential ability to benefit. Time and again, we hear from people whose mental health is actually worsened as a result of constant reassessment and constantly being asked to tell their story again, which adds further to their stress rather than enabling them to become more equal citizens in our society.

**Q120 Glenda Jackson:** So really, changing the name is irrelevant if you do not ensure that the relevant information is out there for everybody concerned.

**Paul Farmer:** If the name did what it said on the tin, to coin a phrase, that would be great. If people’s understanding of “disability living costs allowance” is precise, that is fine, but if people are unclear about what PIP means and stands for, it adds further to confusion. Fundamentally, it is about what is inside that box.

**Q121 Glenda Jackson:** It is quite scandalous that people still do not know that it is a benefit that you can claim in work as well as out of work. That is absolutely outrageous.

**Geoff Fimister:** The question about the awareness levels of various professional groups is something that certainly resonates with me. I ran a local government welfare rights service for 25 years in Newcastle upon Tyne, and part of our brief was to try to provide training and information systems to other professional groups such as social workers and housing staff who were in touch with claimants and potential claimants. It is a complex business.

The counter-argument that people used to put to us was, “The benefit system is so complicated, how can you expect busy staff to understand it?” As far as it goes, that is a reasonable point, but we used to argue that it is essential to have at least a reasonable diagnostic level of knowledge so that you know when there is a problem and you can see that someone is under-claiming. Even if you do not have a detailed knowledge of the system yourself, you at least know that you should be referring that person for a benefits

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check. That was always our objective: to try to get at least a decent diagnostic level.

We did a lot of work nationally on this as well through the local authority associations and through the social services trade press, and we found a great deal of variation from one local authority to another in the extent to which they took that on board. There is also a link in here with staffing levels, because if you are jostling to try to get welfare rights into a training programme, you are taking up part of the staffing margin that is allocated for training. When you are in a situation of staff shortages, training tends to be one of the first things to go, unfortunately.

**Chair:** We will move on to Oliver, who also has questions about the need for change.

**Q122 Oliver Heald:** Just on the matter that we have been discussing, do you think DLA has an image problem? Certainly, when Professor Fothergill was talking to us he was describing the concentrations of DLA claimants as being in post-industrial areas in South Wales, the North and Scotland. He was saying that you are talking about people who are poorly qualified, from manual occupations, who have been out of work for a long time, with formidable labour market detachment and similar household types and housing tenure. Really, there was a flavour of labour market problems in an area, continuous unemployment and people gradually being diverted into benefits of this kind. If that is the image of DLA, you can understand that it might be quite difficult to sell it in areas where there is not so much of a labour market problem, and you would perhaps be talking more about an in-work benefit than an out-of-work benefit. I wondered whether you wanted to comment on the image of DLA.

**Amanda Batten:** I think in some ways the image of DLA can be quite positive. It is a benefit that people really value because it is about having that money for you to use as you know best, as will best support you. It is one of the benefits that our members would almost value most, because you have that flexibility with it. We were surveying our members' views and lots of people described it as a lifeline. In some ways, because some people will have applied for DLA for children or have used DLA for a long time, their understanding can be higher than it is about some of the other newer benefits, particularly for younger adults. So I think it is mixed perhaps.

**Neil Coyle:** I think the image problem is interesting. I would perhaps challenge some of that. If you are out of work for a long time and you have worked in heavy industry, it is not that you are gradually pushed on to claiming something because there is no other potential income, it is probably more likely that you gradually end up meeting the criteria through the deterioration in your health in being out of work for so long. There are other reasons for the uptake being higher in those areas perhaps. But the image problem is perhaps a *Daily Mail* one, or a misperception of what people are using it for and what it is supposed to help achieve. That comes back to the communications and reaching a better understanding of this or any other benefit. What is it designed to achieve? Is it helping to do that? Is it helping people to meet the costs of living?

These issues are all improvable under existing arrangements or with tweaks to the existing system, rather than paying a very hefty sum to introduce a new benefit, which will have a far greater image problem from day one because people will be moving off support on to, potentially, nothing.

**Paul Farmer:** I am not sure that it has an image problem. It has an invisibility problem in the eyes of many people. We think it is quite significantly under-claimed. Many people do not even know it exists. Although there is a risk of DLA being rolled up with a variety of other benefits, there is a popular misconception or perception about people in the industrial heartlands who have accumulated significant amounts of benefits. Neil is correct. We know that spending long periods of time out of work is poor for your mental health, for instance. It will increase the incidence of mental health problems. So there is a genuine issue around that but more broadly, the media conflate DLA into out-of-work benefits, and those kinds of messages, especially ones that suggest that is easy to claim the benefit, definitely suggest that there is a misconception problem. Anybody I have sat with who has tried to fill in the form will tell me quite how complex and difficult it is to claim the benefit. It is an extremely difficult benefit to claim.

**Geoff Fimister:** The point about the old industrial areas is very interesting. I thought Steve Fothergill's argument was impressive and I think he is right. Clearly, with the decline of the old industries a lot of ill health, as Neil says, is due to people being out of work for a long time, but it is partly also because some of those industries are associated with health problems anyway. Clearly if people who have been on a decent wage now find themselves living on very low levels of benefit, it is important for them to be able to maximise their income, not just through DLA but through whatever benefits might be available. It is not a coincidence, I think, that the old industrial areas and some of the poorer London boroughs were also the pioneers of local authority welfare rights strategies as well. What we also found at Newcastle Welfare Rights was quite a lot of low-paid workers who were failing to claim the benefits that they were entitled to, maybe people who had previously been in heavy industry and gone into lower paid jobs. When we did take-up work with low-paid workers, we were constantly finding unclaimed benefits, not just disability benefit, but housing benefit and council tax benefit as well.

**Eugene Grant:** I would pick up on the point about maximising income. It is not necessarily about maximising someone's income; it is more about recognising that their income takes a significant hit because of the additional costs of being disabled. Those costs and barriers will arise whether you are in a rural area in Wales with a post-industrial job or industry, or in a city such as London. It is very important to recognise that it is about meeting those additional costs, not necessarily maximising one's income in that way. I definitely second Amanda's point about DLA being an extremely valued benefit that enables people to participate. It occupies a unique space in the welfare system.

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**Q123 Oliver Heald:** I was not supposed to be asking you about that. When they did the national benefit review in 2004–05, one of the things that they found is that there is a very low level of fraud and error for DLA, but one issue that was identified is that there could be gradual changes over time that are almost imperceptible day by day but that over a period of time lead to overpayments being made of about £0.6 billion a year, which is quite a significant amount of money. Of course, that is the basis for the argument that we need systematic reassessment, otherwise we will have this problem with the budget. What are your comments on that? Obviously some people are not in favour of systematic reassessment, but surely the taxpayer is entitled.

**Paul Farmer:** In the system as it currently exists, some people will be given an unlimited award and others will be given a time-limited award.

**Oliver Heald:** Well, 70% are indefinite.

**Paul Farmer:** There is no reason within the current system why you could not build in some more time-limiting, particularly for those people who might have particular conditions. But it is equally the case that there are large numbers of disabled people for whom their condition will not alter over a long period of time, so it feels unreasonable to expect them to undertake a regular reassessment when their condition is permanent.

For people with fluctuating conditions, you would have to have a system that is suitably sensitive to the nature of their fluctuating conditions. As this Committee will be aware, that is one of the issues on which we have been seeking to work with the Department in the context of the Work Capability Assessment, which in its current form fails to be sensitive to the nature of fluctuating conditions.

So I think there is a balance that needs to be struck between appropriate levels of reassessment and learning lessons from the Work Capability Assessment journey. For instance, with mandatory face-to-face assessment and not taking full account of previous medical evidence, there may be a better way of doing it than simply following the model that is currently being applied in the WCA, which has extraordinary similarities to the current proposals for the PIP reassessment process. There are some very significant dangers in simply taking that template and applying it to this particular benefit for a number of reasons that colleagues have mentioned.

**Q124 Oliver Heald:** Just to challenge you a bit on that, obviously there are mental health conditions where you can have a period of two years, a very long period, where you are really in quite a good place and then a period where things go badly wrong. Surely you have to be able to reassess a condition like that or it could lead to a situation where you are not paying the right amount.

**Neil Coyle:** That is possible under the current system. The Department for Work and Pensions can require a review of any DLA payment.

**Q125 Oliver Heald:** The point that I am making is that it should be a systematic reassessment, otherwise the budget is at risk.

**Neil Coyle:** Even that is possible under the current system, and we normally have the evidence on, “What is the primary condition? What are the other conditions? Are they likely to change? Would it be sensible to be calling people in for review bi-annually?” Or whatever it might be. The Department for Work and Pensions has that power under the existing arrangements.

**Q126 Oliver Heald:** But given that, at the moment, 70% are indefinite, that is a very substantial percentage, isn’t it? What is the percentage where you would say, “Well, there shouldn’t be any reassessment”?

**Amanda Batten:** I am not sure there is a precise percentage, but there is a need for some flexibility and pragmatism in the system. For some people a regular reassessment might be appropriate and achieve the outcomes you are describing, and of course, people’s needs can change and become more complex, so they might need additional support as well as the reverse. But for some people, if you had rigidity in the system and everybody had to go through a systematic reassessment on the same basis, it would be impractical and unnecessary. Somebody with profound autism has autism for life. They are not suddenly going to not have autism. To put them through a regular reassessment every year to find that they still have autism and those needs—there are also cost implications. It seems an unnecessary use of resource. You need to make sure that the system has the flexibility and pragmatism to reassess as appropriate.

**Eugene Grant:** The idea of a systematic reassessment jars slightly with the Government’s personalisation agenda. As Neil says, a lot of personal information is there. If anything, those assessments should be based on that personal basis, rather than a systematic thing where every two years you reassess everybody.

**Geoff Fimister:** I think that reassessment can be very useful in both directions. It can pick up where somebody is being overpaid because of changes over time, and also pick up where they have been underpaid because of deterioration in their condition. That is fine. The problem is that it has become a bit of a fetish in the current review. For example, in the sensory impairment context, if you have somebody on the highest rate and they are not going to get any better, what is the point of reassessing them? At the moment, severely visually impaired and deaf-blind people have indefinite awards and automatic entitlement. That seems only sensible. To introduce an assessment for no apparent good reason seems to us to put unnecessary pressure on those people. Also, to pick up the previous point, it is a waste of administrative resources and runs against efforts to introduce more streamlined administration into the benefit system.

**Paul Farmer:** First of all, I would be surprised if significant numbers of people with mental health problems received indefinite awards. Bearing in mind that it is a relatively small number of the overall category, I would be surprised if it were a significant number, but there are certainly examples where that would be appropriate. For somebody with very severe

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schizophrenia, for instance, that would be very appropriate. But we are certainly not opposed in principle to the idea of reassessment.

I suppose my point is that we need to take the learning from the WCA process. We know that in the current WCA process, that reassessment is extremely stressful to people. It creates high levels of anxiety and concern. We think that there are pieces of evidence that could be usefully used to make that reassessment process more rounded and effective. In particular, to pick up on the point about the join-up with health, health evidence could make that a much easier process.

Of course, the nature of people's fluctuating condition is such that sometimes, the benefit is the difference between keeping them well and making them unwell. It is a difficult assessment to make—we completely understand that—but what a number of people tell us is that this is the kind of benefit that makes quite a big difference in terms of people's ability to live a relatively normal life.

**Q127 Oliver Heald:** But you do accept that if £0.6 billion is being overpaid, you can't ignore it.

**Paul Farmer:** No, and in principle, reassessment is not a problem. The question is about how you do it and how systematic it is.

**Geoff Fimister:** Just for clarity, I should have said that I was referring to the mobility component.

**Q128 Oliver Heald:** My next point is about the rigour of the system. Only 6% of the awards are made on the basis of a face-to-face assessment. Do you think that that is not rigorous enough, and that far more effort needs to go into it?

**Neil Coyle:** I think this is the same point that Paul has just been making. If there is sufficient additional evidence, why would we impose or require a new test that costs money to run that would outweigh the likelihood of finding different information that would result in non-payment of benefit?

**Q129 Oliver Heald:** My question is more about balance—6% is a tiny proportion. You are right that in some cases it will be clear from other evidence, but should there not be far more face-to-face assessment and a really rigorous approach?

**Neil Coyle:** Something like 56%—if I'm right—if of DLA recipients have four or more health conditions. If they have information to back all that up—clearly, costs are attached to that—56% are already accounted for.

**Q130 Oliver Heald:** So move up to 44% face to face.

**Neil Coyle:** That's four or more health conditions. Within that 44%, I do not know what the figure is—the DWP would be in a good place to say how many people have three conditions. If there is sufficient medical evidence for those, again, the cost of requiring someone to come in for face-to-face assessment—the sheer level of bureaucracy involved—is unhelpful given the limited resources that are being distributed.

**Chair:** Part of the problem around this argument might be that the Government do not trust the

evidence that is coming in. That you cannot trust GPs to do a sick note any more seemed to be suggested this weekend.

**Q131 Sheila Gilmore:** Perhaps I can ask whether you think it depends what a face-to-face assessment is about in terms of the benefit. Obviously, there are medical reports and so forth. Is it a medical assessment to double-check the information? What do you see the face-to-face assessment—if used—being for?

**Amanda Batten:** Our primary concern is around the change in the assessment process to introduce really heavy reliance on face-to-face assessments, because we feel that that change will disproportionately impact on people with mental, cognitive and intellectual difficulties. That draws on our experience of the assessments around the WCA for Employment Support and Allowance (ESA), on which there is a very high rate of successful appeals, as you know—certainly around autism.

There is difficulty with the face-to-face assessment. We would love everyone doing those assessments to have really good training in autism, to be able to communicate with someone, to be able to do an in-depth assessment and adapt their questioning to get the information they need, but that is unrealistic in the context of 80% of GPs saying that they do not have understanding of autism—and that is to refer for diagnosis, let alone to do an assessment of that nature. If face-to-face assessments are done by people with limited training or knowledge, it seems unnecessary to do them if claimants have just had a diagnosis and a comprehensive report from a psychiatrist, or whatever. They might have had a community care assessment and been able to put all that evidence forward. It seems unnecessary to insist on a quite limited face-to-face assessment following that. What is really important is that there is a tiered process to assessment, in which, if you have the evidence on paper, you do not need to go forward. The important context, as you mentioned, is around the very low fraud rates for DLA—it is useful to bear that in mind, but we must also be realistic about how in-depth and effective face-to-face assessments on this scale can be.

**Q132 Oliver Heald:** Do you think that the criteria have broadened too far, because three times as many people are claiming as a few years ago and four times as much money is being spent. Does that suggest that the level of disability required in order to get the benefit has dropped?

**Eugene Grant:** I don't think we should necessarily regard the rising caseload and expenditure as a bad thing. We are not talking about an out-of-work benefit; we are not talking about the economy being in crisis and saying, "So many people are out of work and claiming jobseeker's allowance—this is rocketing." What we are talking about is a benefit that enables disabled people to participate in society, and it is very valued, as my colleagues have been saying. I do not necessarily think that the fact that the caseload has gone up is a bad thing. But if you narrow it down more, we know that people are getting older, more people are surviving into later age and more

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premature babies with conditions are surviving, so there are demographic reasons for why the caseload might have increased.

One of the interesting things about when the Government talk about their reforms is that they often describe the overall caseload and overall expenditure, but then they are only going to be reassessing working age claimants, so there is a discrepancy in the figures there. I do not think, however, that we should necessarily be automatically assuming the rise in DLA caseload to be a bad thing.

**Q133 Oliver Heald:** Do you think it is easier to get it than it used to be?

**Neil Coyle:** It remains the same assessment process, and the eligibility criteria are the same, so I do not think that that is the issue. To flesh out a little bit more what Eugene has just said, I think the 30% figure that was used by the Government at the start of the call for change has been looked at by the Department for Work and Pensions and the working age growth is closer to 13% once you take into account the population demographic change. Some of that is about the fact that it was a new benefit from 1992, as well as the demographic changes and some greater level of awareness that there was a bit of support available.

**Geoff Fimister:** I entirely endorse both of those—

**Chair:** I must stop you there. We need to move on, because we actually have not got on to the new benefit yet, so we will do that.

**Q134 Andrew Bingham:** Question to Neil: the DWP said that you have made an assumption that current lower-rate DLA recipients will not get PIP, and the DWP has said that that is simply speculation because you have no evidence to base that assertion on. Do you think that is a responsible line to take? In Port Talbot yesterday, one or two people were concerned that they would lose the lower rate. It seemed to be a done deal. Do you think that that is a responsible line for your organisation to take without the evidence?

**Neil Coyle:** Right. The mission statement of Disability Alliance is to break the link between disability and poverty, so it is our charitable obligation to look at anything that risks increasing disability poverty. What we have had in the DLA/PIP announcements is a 20% arbitrary figure being put on what will come out of DLA expenditure without a justification for what that figure is based on ever being provided. Freedom of Information requests that have gone through have said that it would fetter decision making if the process to decide that 20% figure was revealed.

The figure that we have used is based on looking at total low-rate care DLA expenditure for the working-age population, which is £663 million a year. Even if all of those people lost all of the support that they receive, that is just about half of what the Government are looking to take out of the total DLA pot by 2015–16, and the Government's plans include shifting the three rates of DLA care into two rates of PIP daily living component. The Government's language has been very strongly about providing support to those with the greatest needs, and, under the DLA model that we have now, those with the greatest needs are those who receive the greatest levels of payment. The

group on the lower rate is clearly most at risk, and even if all of them lost all of that level of support that they receive, the Government would still not meet their savings target.

**Q135 Andrew Bingham:** It is still an assumption though, is it not? You have still made an assumption.

**Neil Coyle:** I would suggest that it was an estimate of who is most at risk. I would very much like to have had the Department for Work and Pensions provide its own estimate for who is most at risk, and we have been promised that for some time. In the latest commitment, it was supposed to be in the, *Personal Independence Payment: second draft of assessment criteria* document, which came out last Monday. We were supposed to have in there an estimate for who could lose out in this system. So we are working in a vacuum, and, as I say, I believe that it is our responsibility to highlight who could be losing out and what the potential impact of losing out could mean.

There is something else missing, which is what DLA helps people achieve, what could the cost to Government be and what could the risks to the individuals and their families be of withdrawing support. We are doing that because the DWP is not providing that level of information and therefore generating huge anxiety for disabled people, because if the reduction in expenditure target is 20% and if it is not this group, who is it?

**Q136 Andrew Bingham:** I will just pick you up there. I am not 100% sure of your wording, but you say the target is 20%. I do not think that it is a target; it is what the Government estimate. We have heard your assumption as to who will be worse off through the introduction of PIP—the people on the lower rate. What is your assumption of who would be most likely to benefit from PIP?

**Neil Coyle:** Because of the way we expect this to change, and we are not told yet what the levels of payment might be, that is a difficult one to answer. If the levels of payment are the same, we will be requiring two million working-age, disabled people to go through a test so that some people can retain the level of support they have now. So in terms of being better off, I would argue that very few people will be better off. If the new benefit comes with a better communication awareness campaign for what it can help people achieve, both more generally, but also within other statutory services and beyond, then perhaps there will be some people who don't currently receive support who seek help from the new benefit and they will be better off.

**Q137 Andrew Bingham:** You've not made that assumption?

**Neil Coyle:** Well, the Government is saying it expects some greater level of uptake but meeting that greater level of uptake would mean other people having to lose out. So, better off? It is probably a little bit difficult to see, more because of how the Government has reached the point it has, where it said this new benefit is about creating independent active citizens. We would all welcome that. But this comes with this 20% target. I think the Government has been quite

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clear. It is not an estimate. This was in the Spending Review. It was in the October Budget. It is in the Treasury papers. I don't think there is any question mark over whether this is a 20% target.

**Geoff Fimister:** It is 20% of projected spend. Those are the parameters that the officials are working within in trying to develop the scheme. That could be achieved either through reducing the number of claimants or reducing the level of the benefit, or both, some combination of the two. We have not been able to establish how exactly they propose to go about it. One of the contradictions we found in the discussions we have had with the officials who are working on this is that they are engaged in an increasingly sophisticated exercise which, it seems to me, could potentially increase the spend on the benefit and yet they have to meet this 20% reduction in projected spend, which is more than £1 billion. Given those factors, it is a reasonable assumption that the recipients of the lower rates of the existing benefit are most at risk. It is difficult to see how it could be otherwise.

**Q138 Andrew Bingham:** Okay. Just as a wider question to all of you, what is your assessment of the likely combined effects of DLA, incapacity benefit reforms and the time limits on contributory ESA?

**Neil Coyle:** I think I would add in social care as well. The impact will be profound on hundreds of thousands of disabled people, whichever way you look at the range of reductions in support. Social care is also relevant obviously for councils facing some reductions in their spending levels. Social care is a significant part of any council's budget. Disabled people are receiving social care service support that won't be there. There is another risk. We have already seen the tragic circumstances where people feel they cannot access support now. Some of that support will decrease under the changes you have listed, as well as social services retracting further. We have seen councils trying to move very quickly, like Birmingham and the Isle of Wight, and not paying due regard to the potential impact on disabled people. That is where they have been hooked on the process, rather than making that change and cutting support.

If Birmingham and the Isle of Wight had gone through the right process they could legitimately have cut care support to critical needs only, which would have meant even more disabled people not being able to access support. Of course, the Dilnot review pointed out that if current benefit levels remain the same, which would include lower rate care, care expenditure, demand for care services would be at a particular level. Removing lower rate care, causing the escalation of need and the higher demand for services will put even greater pressure on other public services. So not just the profound impact on disabled people but the profound impact on other areas of Government expenditure that is being under-analysed by the Department for Work and Pensions and the Office for Disability Issues across Government.

**Q139 Sheila Gilmore:** I have a very quick question about the overlap there with social care. Are you

aware of what proportion of local authorities take into account DLA income in setting charges for care?

**Neil Coyle:** All councils can claim against DLA for some of the support they provide. Again, where individual disabled people lose entitlements, then councils would also lose. It is a slight generalisation, but if you are getting lower rate care DLA, you are probably less likely to qualify for council care services anyway; there are separate pots there. But if people lose DLA, then councils lose the ability to reclaim the costs of providing services to disabled people, so there is a dual cost there for councils.

**Eugene Grant:** Unfortunately, I do not have the number off the top of my head. Earlier this year, Scope commissioned the think-tank Demos to do a piece of work on local cuts to local authority budgets and how that would impact on disabled people. That took into account which councils do take people's DLA into account, and it was quite a significant number, which I do not know off the top of my head. It is really important to stress when we talk about DLA and social care that they are completely different things and are for very, very different purposes. One is about the prevention of risk to a person's own well-being and making sure that they can participate in their community and get support, such as for eating and things like that, while DLA is very much a participatory benefit about additional costs and barriers. They are very different things.

**Geoff Fimister:** It is a conundrum for local authorities, which the more thinking local authorities are aware of, that if you can encourage people to claim DLA and then charge against it that obviously helps you to provide services, but if you charge too much and leave people with very limited disposable incomes that makes it more difficult for them to cope in the community, and therefore they are more likely to need services.

**Q140 Karen Bradley:** I would like to turn the conversation to the required period condition. The DWP has said that it is going to extend the qualifying period to six months in order that the definition of long-term disability for PIP is the same as it is in the Equality Act. First, what are your thoughts on whether you agree that that is necessary and, secondly, what do you think will be the consequences of a six-month qualifying period?

**Eugene Grant:** I think it is a regressive move. When you are looking at a benefit that is specifically designed to help people cover the additional costs of disability, someone who has a sudden onset of a condition—a stroke, for instance—will now be made to wait longer before they can access the support they need. For want of a better word, someone who has a condition like that has a kind of "start-up" cost, if you will, of adapting to that change in their life, having to adapt their house and having to meet other additional costs, and they will have to wait longer to get the support that they will be entitled to.

**Paul Farmer:** I would agree with that. It is so important that when people are experiencing a problem that they are able to get help as quickly as is reasonably possible. Particularly thinking about those people who are in work, we know that that period is

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often one where people can very easily slip out of work and, as a result of that, find themselves on benefits and costing the state significant amounts more of money. We understand the issue around the Equality Act, but a 3:9 split is a better one than a 6:6 split.

**Geoff Fimister:** I would agree entirely with those points. For people with sudden onset conditions—for example, in sight loss, for somebody who has suddenly lost their sight for some reason—it is a time at which they are facing huge problems, and having to wait six months for financial support in that way is just worrying. We are very strongly opposed to that.

**Q141 Karen Bradley:** Three months is okay for people at the moment, is it?

**Geoff Fimister:** Obviously, the sooner the better as far as the individual is concerned, but three months is obviously a lot better than six months.

**Neil Coyle:** The point has been made that to make the change—to make the qualifying period longer—would undermine people's early intervention. Given the evidence on getting support to people quickly, particularly those in work—the Government have a very strong agenda about supporting people in work—to change this and prevent people accessing support in work would risk employment.

**Q142 Karen Bradley:** But there is general acceptance that the definition needs to be consistent across the Equality Act and PIP, or whatever it gets called?

**Geoff Fimister:** The arguments about six months fitting in with the Equality Act we took to be a bit of an *ex post facto* rationalisation for what is a financial saving.

**Q143 Harriett Baldwin:** If you are in employment, is it possible that your needs might be to some extent covered by your employer? Does that ever happen?

**Neil Coyle:** You might get reasonable adjustments from your employer; obviously, there are legal obligations. If you have, for instance, a sudden spinal injury, it can take a very long time to get support in work, even through Access to Work. I am sure we all have sorry tales about how difficult it can be to get a disabled employee Access to Work support. It is about personal support, such as suddenly needing an adapted vehicle if you have spinal injury. An extreme example, which might not be suitable, is trying to get a suitable wheelchair, although that is perhaps not the best example. The employer will only need to provide an adjustment for you to be able to do your job, so that is once you are in work—in a physical building. There are other personal considerations, such as transport. I am not sure whether I have given the best examples.

**Q144 Chair:** You seem to be arguing that the shorter time period is appropriate, but only in some circumstances—somebody who is suddenly blind, who is not going to recover, or somebody who had a cataclysmic accident and is suddenly a paraplegic, who is not going to recover. Surely the Government are trying to make sure that the benefit only goes to

people who have got a long-term condition. Blind and paraplegic are long-term conditions, and you know from day one that they will be, but most other conditions are not. Aren't the Government quite reasonable to say that in the generality there is a much longer period? What you are arguing for is in specific situations—this point was certainly made at the meeting yesterday—three months is too long, and it should be no waiting time. Is that what you are arguing, or are you saying it should be a short time for everybody?

**Neil Coyle:** Geoff mentioned three and nine, so it is not that the entire qualifying period would change. You would still have to be experiencing something for 12 months. Most of the people who would be eligible, we would imagine, would have experienced something for longer anyway. When you approach DLA you would have had that experience for a significant period. The points that we are making have all come about because we have all been active in working with the Government to try to look at who could be most negatively affected by changing the qualifying period. That is why we used the sudden impact examples.

**Q145 Karen Bradley:** But aren't they still affected by the fact that they have to wait three months? Is there not a case for reform that a sudden impact, as the Chair has said, which is clearly going to last more than 12 months, should not even have to wait three months?

**Geoff Fimister:** You could certainly argue that, yes.

**Paul Farmer:** The point you are making is about recognising that the condition is going to be for a period of more than 12 months. The question then becomes at what point you make the assessment. There is often a need to allow a slightly longer period of time to understand whether that will be a very long-term condition. For people with mental health problems, for example, it might take a little while to understand exactly how long that condition will last, and of course it is not always possible easily to tell. However, I think in many cases there are sufficiently clear signs that will indicate—that is why taking medical evidence is important—how long a condition is likely to last. I am thinking, for instance, about a young person who may be experiencing a diagnosis of schizophrenia or bipolar disorder for the first time. It is pretty clear that they will experience that disability for a reasonably long period, probably for the rest of their life. We know that getting somebody help as quickly as is reasonably possible gives them a better chance of recovering and being able to play an active part in society, so there is a good argument for getting the help as early as possible. Waiting for too long—at the moment, the proposal is six months—can elongate the length of time before a reasonable recovery is possible. I think there is a balance to be struck here, isn't there?

**Q146 Glenda Jackson:** I have a constituent who has a gradually debilitating disease. She has a very understanding employer, who wants to keep her. It is a physical deterioration. The problem is that he is going to have to change her physical environment,



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which will take some time. So is she going to be in or out of this kind of system? There is going to be a point where she cannot actually get to work, but that is not her fault; it is because the employer has not brought about the necessary changes to enable her to work there. Obviously she can do part of the work, which at the moment she may be able to do at home, but that in itself is a difficulty because, of course, her own home is going to have to be changed.

**Chair:** I am not sure about that, because it is far more to do with Access to Work and employers.

**Glenda Jackson:** The point is that she is claiming it at the moment. Do you see what I mean? That suggests there is not just a sudden impact here.

**Chair:** I think some of that will be assessment, and we have questions on that to come.

**Q147 Harriett Baldwin:** I just wonder whether if what we are picking up here is that there is a capital need—you might have adaptations or equipment that is a one-off—and then there is an ongoing living cost need for the additional costs. Is it possible that, as part of this reform, the Government ought to consider breaking the allowance down into those two elements: an up-front cost and an ongoing cost?

**Eugene Grant:** I would say no. I think there is a real risk with assuming that certain costs are one-off, because really they are not if you look at them. We are in contact with people daily who tell us about powered wheelchairs, for instance, which can cost up to £8,000, but when they break down, you have a battery that costs £600 and tyres that cost £70. The maintenance of what you thought was a one-off cost has significant knock-on effects, so it is very difficult to break it down from a one-off cost to an ongoing cost of living. The same goes for housing adaptations and for those big chunky costs that often throw disabled people because they do not have the financial stability to meet them, which is what something like DLA will provide.

**Neil Coyle:** It would have been helpful if the Government had engaged with organisations before presenting certain proposals, because looking at costs would have been preferable. With the Government agenda of coming back to work, making additional payments to help cover the higher costs of entering work could have been very useful within the context of this benefit and helped to tackle some of the misperception that this is not a benefit designed to support you in work as well.

We would have quite welcomed a focus on helping with higher costs at specific times, as well as routine ongoing costs at whatever level they may be. Focusing purely on costs: it is a very low percentage, but there are disabled people who have told us that DLA more than covers their routine costs. It is 2% or 3%, but there is a figure. Having different levels of payment could have generated some savings for the Government while also allowing higher levels of payment for those with even higher costs of living. We are not in a situation with Government where there are clear proposals on the table, and we do not expect it to include variations on levels of payment based on the sudden impact of a change or more routine costs.

**Eugene Grant:** I think one of the most difficult things about what we are looking at is that, with both DLA and PIP as it stands at the moment, it is very difficult to pick up on many of the costs that disabled people have because they come from social-environmental things—barriers to disabled people—rather than just their impairment or the limitations arising from their body or their cognitive, physical or mental impairment. It is actually very difficult to try to flag these costs because we do not, as of yet, have an assessment process that tries to see those barriers from which disabled people incur extra costs, such as from their housing and those kinds of things. It is very tricky.

**Q148 Karen Bradley:** Is this an opportunity for the Government, by making it a personal independence payment, to make it personalised? If it is sudden onset, it is a quicker payment that might involve some form of capital up-front expenditure that is required because of the condition and then an ongoing payment. It should be personalised to the individual.

**Neil Coyle:** There is some space for that, but the message from the Department for Work and Pensions has been very clear that one of the reasons for scrapping lower-rate care was to simplify so that there are fewer mixtures of payments and that there are only certain boxes of support that you could fall into. I am not convinced that the Department for Work and Pensions is in a place where it thinks there will be that variation in the levels of payment. That is not what it seems to be seeking in the drive for simplification, which seems to overrule such a flexible, personalised approach.

**Geoff Fimister:** The other factor is that, although I can see a case for looking at the immediate situation and the possibility of higher payments for some claimants in those circumstances, in a context of significant spending reductions, there is a danger that that might be paid for by reducing the ongoing benefits. That would obviously also have negative implications.

**Neil Coyle:** We see that in ESA, where there is a commitment to pay more to the Support Group—though there is no time frame for that; it is an aspiration of the Government—while at the same time taking a significant number of other disabled people out of out-of-work benefits altogether through time-limiting contributory ESA. We fear we are not seeing a more generous system being introduced.

**Q149 Karen Bradley:** Linked to that, from the evidence there appears to be a difference of opinion between organisations about automatic entitlement. DWP has said it does not want to give automatic entitlement to specific medical conditions, because it says it effectively labels disabled people, and it wants PIP to be more personalised. I know the Disability Alliance disagrees with that. Neil, could you elaborate on your concerns about that, and then the rest of the panel let us know their opinions?

**Neil Coyle:** We have already touched on some of the reasons. To take one relatively small group but with significant barriers to inclusion: deaf-blind people. There is medical evidence to back up the condition

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and it is unlikely to change. Your cost of living is unlikely to change over a significant period. Why would we require an ongoing assessment, of however long? Why would we insist on the costs of running such an assessment process, when those circumstances are unlikely to change?

**Geoff Fimister:** This is the point I made before, where you have a situation such as higher-rate mobility being automatically available to deafblind people and people who are severely vision impaired. It seems totally pointless not to have an automatic entitlement system there. It seems a more unnecessary administrative process. I don't think anybody is arguing that there should be large numbers of automatic entitlement categories, but there are certain categories where it seems quite clear-cut.

**Q150 Karen Bradley:** You would like to see automatic entitlement for certain specific conditions, but accept that there are other conditions where there are differing levels of need and support required, and therefore a personalised approach is more appropriate.

**Geoff Fimister:** Yes. As I said before, it cuts both ways. You can identify underpayments as well as overpayments, where assessment is appropriate.

**Neil Coyle:** Perhaps I should say that Disability Alliance is not saying automatic entitlements for everybody. That is worth adding, I think.

**Q151 Glenda Jackson:** My question is on the personalised approach. I do not quite know how that is going to be delivered. Do you have any ideas? We could look at the present systems of assessment. We have been talking about face-to-face reassessments, and we know that doesn't happen even now. One face is usually looking at the computer screen and not the applicant. Do you have any ideas of how that personalised approach could actually be delivered, given what we know up to now?

**Neil Coyle:** There are mixed messages on this. If we look at the draft assessment, the message is very mixed. While the Government say they want a personalised system, they say there also has to be consistency in awards.

**Q152 Glenda Jackson:** There is a paradox there.

**Neil Coyle:** Absolutely. What the consistency appears to be based on is certain people with certain impairments or health conditions getting the same level of payment, which totally contradicts the idea of having a personalised system. It is a very confusing position to be in.

**Q153 Glenda Jackson:** That is the outcome. My concern is the initial assessment. Do we have any idea about these personalised assessors, the people who are going to do a one-to-one? How is that going to be delivered? It is not happening now.

**Chair:** I think Glenda is asking whether it is going to be Atos.

**Glenda Jackson:** No, I wasn't.

**Neil Coyle:** I think 37 different organisations have put in initial bids to run the assessment process.

**Q154 Glenda Jackson:** So it is going to be the same old system, but with a different acronym.

**Neil Coyle:** It could be. I suspect it won't be Atos for a mixture of reasons, but there are also organisations looking to involve disability organisations in the process at some point. We think the Department for Work and Pensions is quite keen to explore that further, but exactly what it looks like we do not know yet.

**Eugene Grant:** There has not been a huge amount of detail yet as to the delivery of the Personal Independence Payment and who the assessors will be. I think it is quite clear that if you look at the policy objectives around DLA reform, which is to ensure that disabled people who face the greatest barriers to independent living have support, you are going to need assessors who understand those barriers and that not all of them will come from medical impairment. Many of them will come from other things in the same person's life—their social barriers, practical barriers—so whoever does the assessment needs to have a good understanding of the barriers that disabled people face.

The roll-out of the personalisation agenda really helps with that, so you are seeing people with expertise in support planning and things like that—a much more personalised, holistic approach rather than a strict medical tick-box assessment. I think that really has to be kept in mind.

**Paul Farmer:** For that reason, we would really support a very gradual pace of transition, if that were to be the ultimate outcome. We have learned a lot from the WCA system, where we have seen the reality of that being applied over a couple-of-years period only to new claimants. That is all very well documented; I won't go into that in great detail now. There are significant risks in getting this assessment process badly wrong. So taking it gradually, recognising that there is actually quite a lot that you can do to make the current paper process a little bit more effective, taking into account other forms of evidence to enable people to be able to make the right decision feels like an approach that you could take.

There is an assumption being made that face-to-face assessment is automatically a good thing, and I think we would challenge whether face-to-face assessment is automatically a good thing. Good-quality evidence being provided and being assessed by well-trained and well-understood assessors can be just as effective a tool. There may be a need for face-to-face assessment, but the current plans suggest an extremely speedy migration of current claimants across. Particularly at this particular time, there is a very strong argument for that migration being phased in in an appropriate way. The damage that has been caused as a result of the WCA process, in terms of many disabled people's trust in these kinds of assessment systems, should not be underestimated.

**Chair:** However an assessment is done—whether it is face to face or on paper—it will be based on the criteria, which is our next set of questions, so we will go on to that with Sheila.

**Q155 Sheila Gilmore:** Eugene, you have mentioned the use of social and environmental factors and,

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indeed, your organisation has produced a paper, in conjunction with others, with a different way of perhaps carrying out assessment. Isn't there a danger that if you do that you produce something that is going to be even more subjective—that has been one criticism of the current system—and actually quite cumbersome, both in terms of what people would have to fill in by way of forms and the information they would have to provide?

**Eugene Grant:** There is a real danger with this that we are getting a lot of talk about something that is objective and subjective. None of the assessments we have been talking about today are objective. What we have been saying is not only that if the Government are to fulfil their obligation to ensure that the same people who face these barriers to independent living get support, they need to understand those barriers—by way of a personalised approach, it has to be relatively subjective in that sense—but also that the Government have made a commitment to the social model of disability, which understands that many of the barriers disabled people face come from society. To fulfil that commitment, they need to take into account those kinds of barriers as well.

While we understand the Government's concerns about subjectivity, there is a risk that the emphasis on objectivity is being used to justify a more simplistic approach that focuses much more on medical impairment than the actual barriers that a disabled person faces in their everyday life, which will come through different factors. The important thing is to accept that there will be two people with the same impairment who will have different barriers, who could then be entitled to different levels of PIP. I think we support that, because it should be about the barriers that they face, not necessarily their impairment. Some barriers will come from their impairment, but some will come from other sources.

**Q156 Sheila Gilmore:** If the factors that you suggested should be taken into account to amplify the assessment happened, would that not broaden eligibility to more people and therefore defeat the object of reducing expenditure?

**Eugene Grant:** Not necessarily, because there will be some people who have impairments but very low barriers. When we did this research with Demos a year ago, we found that many of the barriers that disabled people faced came from housing, transport and similar issues. You could have somebody who would have a certain impairment, but who lived in appropriate housing that was perfectly adapted, had a Motability car—not that that does not come without costs—and had a great network of support and informal support. The barriers that they faced would be lower than those faced by somebody who has what would be seen as a low-impact impairment or a less visible impairment, but who faces very significant barriers.

**Q157 Sheila Gilmore:** We have just had another set of draft criteria published, and the Department feels that it has built on the views that were given through the process by disabled people and organisations. What is the response to the new draft?

**Eugene Grant:** Could I just jump in on that? To quote from the new draft, the broad principles of the criteria remain the same, so we have seen little change from the first draft to the second draft. There have been some tweaks and edits here and there, which are quite welcome, such as including recommended medication—we know that that has significant costs—and not just prescribed medication. Generally, the overarching principle underlying both assessment criteria is about the definition of ability: an individual's ability as defined by their cognitive, mental or physical impairment. As we have been saying today, that only gives rise to a certain number of those barriers and not the whole picture. Until you begin to include wider factors, the assessment criteria will only help assessors so much in establishing what barriers disabled people face.

**Geoff Fimister:** In the specific context of sight loss, we feel that the second draft indicates that DWP officials have been listening to what we have been saying. We think it is more sophisticated than the original set, particularly in the areas of communication and social engagement. The DWP has taken that on board, and as far as it goes we are pleased with that. The big worry is that we still know nothing about thresholds. Until we know that, we do not know what the impact is going to be. Having a more sophisticated set of descriptors is not going to help us if the points system and the thresholds still rule people out of entitlement.

**Neil Coyle:** We have significant concerns, and we will respond to the Department for Work and Pensions. It is welcome that the Government have moved a little. The Department for Work and Pensions has improved the test, but it also acknowledges that the initial test was pretty poor. One of the biggest fears we have is that the Government are not allowing themselves enough time to get the test right. Although they acknowledge that the first test was poor, the results of testing that test on 900 people will form the basis for rolling out the entire new test to two million working-age disabled people. Although we still have some opportunity to improve it, there does not seem to be the time, space, energy or commitment to ensure that whatever new test is finally developed is trialled sufficiently to avoid some of the situations we have seen under the Work Capability Assessment. We are due another set of recommendations as to how to improve that further, three years after it came into operation, after £80 million has been spent on the tribunal service in the past two years to try to pick up some of its faults.

**Amanda Batten:** I agree with both those comments. The first set of descriptors were very disappointing and very limited. The second set are significantly improved, from an autism perspective at least. They much better capture difficulties around social interaction and communications, so there is real progress there. It is always hard to capture a complex disability like autism in 12 descriptors, or whatever it is, and I think the assumption is that some of those descriptors would act as proxies for other difficulties. So, for example, there is a new descriptor on making financial decisions, but not on being able to manage a household, tidy up and keep things clean, which are

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two areas that we were concerned about. The assumption is that if you can manage financial issues, you might be able to manage those practical household management issues, too. Obviously, for a condition like autism where people have a very spiky profile, it does not necessarily follow in that way. The new descriptors certainly reflect autism better than the first set of descriptors and perhaps better than the DLA form, but the nature of the system means there is no scope for that “any other information” box that people use at the moment. It is certainly not perfect.

**Paul Farmer:** That links to the point Eugene was making about allowing greater account to be taken of people’s experiences and circumstances. I agree with colleagues that it is certainly a step in the right direction, but there remains an underlying principle that this is still an overly medical approach to the overall way of assessment. We would support an approach, perhaps a box or the proposals that Scope is making, that allows people to describe their circumstances more effectively.

We share the concerns about the thresholds. One of the examples, for instance, is that at the moment, under these new proposals, planning and following a journey will need to cause “overwhelming psychological distress” in order to meet the threshold. That feels like a pretty high threshold for people for whom we know getting around is a key part of helping them to live an ordinary life, as opposed to being stuck at home and being very fearful of going out. “Overwhelming psychological distress” feels like a pretty high threshold.

**Eugene Grant:** One of the concerns, drawing on what Neil was saying about pushing out this test very quickly, is that we have already seen prospective scores on this assessment when there are still big problems with the assessment itself. It is almost as if the debate is being moved on very quickly with very little opportunity to interject and comment. The second criteria were officially released about two hours before the House of Lords debate, so we are seeing very fast movement. There is a real worry about suddenly pushing it too fast, too soon without proper consideration of what PIP is about, what it should be about and whether the assessment and the resulting benefit will be designed properly to meet the Government’s objective, which, when you look at it, is to ensure that disabled people have support to overcome those barriers. That is actually a very progressive idea.

**Neil Coyle:** The Government is not giving itself enough time to consider the impact: the impact on disabled people is immediately obvious; the impact on health care and social care, which we have talked about to some extent; the impact on disabled people’s ability to work is another issue we have touched on; but, beyond that, there will be an impact on the need for informal care to step in if people are to lose support. It is really important to trial the assessment and make sure the descriptors ensure that, when it is finalised, the impact on the whole family is understood better because we have a very high rate of informal care provision in the UK. There is economic inactivity as a result of informal care provision. Any removal through the new assessment process of

support for disabled people will require even more women, particularly those aged 46 to 64, to withdraw from work altogether or to reduce working hours. That impact really needs to be taken into account by Government, but the time-frame does not seem to allow any sufficient analysis of how the test will be implemented.

**Q158 Sheila Gilmore:** Is it your understanding that this is not going to be re-tested, or do you not have any information on that? It is on draft two.

**Neil Coyle:** We have had the test of draft one on 900 individual disabled people. At the Disability Alliance conference yesterday, the Department for Work and Pensions said that it felt that that was enough of an evidence base to push forward to finalise the test.

**Geoff Fimister:** They have said that they are going to consult again on the new set of criteria.

**Neil Coyle:** That is public consultation.

**Q159 Chair:** Can I ask about the criteria on moving around? A distinction is made between people who can push themselves in a wheelchair quite a bit and those who can’t. Regardless of whether you are an Olympic athlete in a wheelchair or you are me, you still need the same ramps, the same lower kitchen, the same adapted bathroom. You still can’t get to lots of places because of flights of stairs, you can’t use the Underground, regardless of your ability to manipulate that wheelchair. Yet, the difference could be between 10 and 15 points.

Karen made points about the capital expenditure required, for which many people will use their DLA. Often people will borrow from the bank to do the adaptations—because they can’t get it through the local facilities grant—knowing that they have the DLA as part of their income and banks will lend on that. There seems to be no recognition of that in the descriptors. That comes back to you, Eugene, and the barriers. It looks at the person not the barriers.

**Eugene Grant:** Exactly. It looks very much at the person. The descriptors have changed and some of the activities have been broadened, but again it focuses on the principle of ability as defined by your impairment. It takes no account of the barriers that society puts in your way. One of the descriptors is the ability to plan and navigate a journey. You might be able to do that fine, but if you are in a wheelchair you can’t access public transport and have to pay significant costs. Some people pay £20 a time to use a cab to do their shopping.

**Q160 Chair:** Buying food and shopping were in the original descriptors, but not the new ones.

**Geoff Fimister:** That is a specific point that we were going to query. We have a list of specific points and that is one. We don’t know why that has come out.

**Q161 Chair:** We don’t have time to explore all of those today. Presumably, you are doing a piece of work where you are comparing the original descriptors to the new ones, and what you would like to see. That would be very useful for us as a Committee, if we could have that analysis of where the Government have got it right and listened—and

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you have said they have in many cases—but where gaps are.

**Neil Coyle:** There is still one very big risk. While taking into account some of the aids and adaptations that are used and are clearly visible, there is still an assumption that it is reasonable to take into account adjustments, aids and adaptations that are not being used. Given that we have seen the rise in disability hate crime and harassment of disabled people—caused, some believe, by some of the media language used around benefits claimants—there are reasons why people may not want to use a particular aid or adaptation, such as a walking stick. The assumptions behind the assessment are that it is reasonable for the assessor to take into account aids and adaptations that could be used.

**Geoff Fimister:** This question of aids and adaptations we think is very important and we have engaged with the DWP over it from the outset. It seems to me that the crucial point is that if someone is using an aid or adaptation that enables them to be more independent and gets them out and about more, that is going to increase their costs, because they are going to be more active. It raises all those issues, for example, about travel costs. It is not just a question of the ongoing expenditure on the adaptation or aid itself, it is the fact that it makes you more independent and therefore will increase your costs. We do not want to see a dilemma created, a sort of better-off problem, in which people are worried about exploring the aids and adaptations available to them in case it reduces their benefit.

**Q162 Chair:** There is also a limitation on the definition of aid and appliance, for instance, if someone needs an aid or appliance to bathe. I reckon I do, because I can't get into a normal shower and I can't get into a bath at all—unless I have an expensive thing that goes up and down—but that is not included in this. Someone like me would get no points. Have I read it correctly?

**Neil Coyle:** That is certainly the kind of thing we are nervous about. Even there, is the expectation that the assessor will then not just have to have a face-to-face assessment, but actually turn up at the individual's home to check what aids and adaptations are being used? Where does the level of assessment end?

**Eugene Grant:** It is very important to consider where these aids and adaptations come from and the cost of purchasing and maintaining them. The assessment is centred on your physical, cognitive and mental ability. But how does that aid or adaptation help you bathe? Those aids and adaptations often come from a very small set of suppliers at significant cost to purchase and maintain. We know from our research and from our conversations with people daily that that is a significant additional cost for disabled people. It needs to take account of that.

**Q163 Sheila Gilmore:** Does some of this depend on the interrelation between a test and other aspects of the system? One of the criticisms of the WCA process has been the apparent almost entire reliance—at least until the Harrington review, and we are not quite sure what has happened since—on the test. Even things

like that box that people could fill in with their personal statement are not necessarily being taken into account. How do you see the relationship between those two aspects of the whole?

**Amanda Batten:** That is a really important point to raise, and it goes back to the need for a tiered assessment. As you know, disabled people go through multiple assessments in their lives. They go through their assessment for PIP, they go through the WCA and we have a community care assessment for some people. The idea that you need to have a totally separate face-to-face assessment, rather than take into account all that evidence and pull in all the reports and evidence that are available and make a decision on that basis, calling for face to face if necessary, seems really inflexible to us. The description of the assessment process as personalised is a little bit of a misnomer based on the proposals at the moment. Personalised is taken to equal face to face in how the Department is talking about the assessment. Just making it face to face does not make it personalised in any way.

**Geoff Fimister:** The DWP has said that it wants to take into account evidence from a variety of sources including professionals who are in touch with the individual concerned. We would also argue that input from the claimant is important as well, and of course from carers. What the DWP has not indicated is the different weight that it would attach to these different sources of evidence. On the face-to-face point, colleagues have made this point before but there is a certain level of skill and knowledge needed, which in some cases is a very high level, for example with a deaf-blind person. One would not want to see that handled without the necessary level of competence.

**Paul Farmer:** That question is about ensuring a really effective join-up between different systems and really making them work. Amanda is absolutely right that many people are asked to undertake many assessments when there is no shortage of evidence that exists to inform an accurate decision. The problem is often that that evidence is not put in front of the right people at the right time. If the proposal is to introduce face-to-face assessment, it is another argument for taking that process pretty gradually and slowly so that, as with the WCA, we can learn from a real-world application of it. I do not think that the current relatively small numbers of people who have been tested on a previous version really gives a strong enough evidence base for a wholesale roll-out, which in itself, of course, is quite costly.

**Q164 Chair:** So what happens now? Is draft two the final version, or is the consultation period still ongoing? Do you as organisations have a chance to comment on this and change it again? What happens from now?

**Eugene Grant:** I believe we do have a chance to comment on the second draft.

**Q165 Chair:** What is your timescale for that? Do you know?

**Eugene Grant:** I do not think there is one.

**Neil Coyle:** I think the Department for Work and Pensions said that there would be a full, formal, public

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consultation on the final draft. That will not be ready until next year but it will run for more than the recommended period for consultation, which is 12 weeks. There will be other opportunities to improve, but it is still based on an initial draft that is acknowledged to have been very poor.

**Geoff Fimister:** We are down to a level of discussing detail now—to be fair to the DWP officials, they have been pretty accessible, in our experience—rather than larger structures.

**Q166 Harriett Baldwin:** When I have met people with disabilities and mental disabilities in my constituency, one of the things that has really concerned me is that they all seem to have the perception that DLA is just going—that it is just ending—and has gone completely. I just wondered, in terms of Government consultation and communications strategy, what the Government could have done with its communications to prevent that perception from occurring.

**Eugene Grant:** I think it is an ongoing process. In advance of the roll-out of PIP, there needs to be a very, very widespread communications campaign about it. We are speaking to disabled people who still do not know about ESA, and that was rolled out three years ago. This will be a massive change—let alone the introduction of Universal Credit on top of that—so there really needs to be a very far-reaching, concentrated effort to reach disabled people to make sure they are up to speed on what is happening. It would be very difficult to get any way around instilling fear in some people, but I think that they have to be informed.

**Q167 Harriett Baldwin:** Change always causes concern. Obviously, in this particular example we are dealing with people who might be thought to be particularly vulnerable or worried about change.

**Paul Farmer:** Most people would recognise that particularly the early stages of the communications around this were not handled well. It seemed to appear in the first instance in the context of the financial situation, which I think immediately created a link with the financial need to reduce the overall bill and others.

There was a relative lack of information at the early stage. Of course, we understand that that is the nature of the process—you start with a policy intention and then you develop that over time—but there could have been greater clarity about, for instance, the numbers of people affected and the basis for having a new benefit. As many people will be aware, there has been a significant debate about the whole mobility component question, which we have not really touched on today. I think that has raised significant concerns, and that could have been handled a lot better.

It is fair to say that in the more recent stages of the process, as colleagues have mentioned, the engagement with the Department has been better. However, there is still an undercurrent of media focus on this which is really deeply unhelpful. On occasion, some of the data which are press released

by the Department for Work and Pensions is feeding that particular misconception.

**Q168 Harriett Baldwin:** I will get to that in a moment, if I may. I want to ask Neil, specifically, a question. Obviously, the Department has said that it is putting disabled people and the organisations that represent them very much at the heart of the development process, in terms of the descriptors for PIP and the consultation on the proposals. Yet you have expressed such dissatisfaction with the consultation process that you have threatened legal action. I just wondered why you felt a legal challenge to the Welfare Reform Bill and this particular process was justified.

**Neil Coyle:** It is almost going back one step. The Government announced the abolition of DLA for working-age disabled people. It will be abolished, so those people who are concerned are perhaps right to be concerned about what comes next, and there is still an opportunity to change that. Our members and trustees obviously took the decision to press for issuing a letter of claim to the Department for Work and Pensions. It was not just about—

**Q169 Harriett Baldwin:** Issuing a—sorry?

**Neil Coyle:** A letter of claim. A letter of claim is pre-judicial review, so you issue a letter of claim to lay out the nature of your concerns. Our concerns were focused on the process of choosing to target this particular benefit in this particular way—for a clear 20% reduction in expenditure on the working-age group. Why was it not a different percentage? Why was it not the full DLA take-up, for example? We have legitimate questions about how the Government reached the decision to do this and how they consulted on how they would undertake that process, based on whether the Department for Work and Pensions was meeting its own legal obligations under the Equality Act to promote equality of opportunity for disabled people and for carers, for some of the reasons I outlined earlier.

The Government suggested that there was 20% slack to come from this without necessarily analysing the potential impact. We have talked about a lot of this today. What happens to disabled people who could have accessed DLA, whether or not they do now, and are removed from being eligible for support by a new benefit? What happens to families? What happens to the public services? We have seen the level of anxiety among disabled people. Our member organisations and the people who contact us are very concerned about what could happen.

**Q170 Harriett Baldwin:** I totally respect your role in the democratic process, but abolition of DLA versus what is being proposed are two very different things. Do you think your role could have been exacerbating the perception among recipients that this is ending completely?

**Neil Coyle:** That is a very fair question. Were we scaremongering—I think that was one of the terms used by the Department for Work and Pensions? I would have to say no. The reason we chose even to investigate the legal option was because, in the initial

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period, particularly the first 12 months from the announcement of the 20% reduction, there was a total—I would not say exclusion, but engagement and consultation was not bearing any fruit at all. The Department had 5,500 responses to its own consultation, and 1,750 individual disabled people and others got in touch with us to talk about it. All of the concerns, and all of the questions we were asking about whether people had looked at what this could mean for x, y and z, were being totally ignored in the drive to implement the 20% cut.

That is not to say that the Disability Alliance just sat back and said, “Oh, we’ll wait for this and go for judicial review.” We facilitated several meetings between the Department for Work and Pensions and groups of our member organisations to make sure that we were still part of that process. We have been on the PIP assessment development groups, which have been looking at implementation, how to communicate with disabled people and how to make sure that people understand what is about to happen. We have been participating in all of that dialogue. We have been involved in the consultation, as I have mentioned, on behalf of ourselves, NCIL<sup>2</sup> and Radar, and all our members. We bring our members into the debates we have on Government policy.

On the back of not having any explanation for the Government’s agenda, rationalisation for the 20% cut or analysis of the impact on disabled people and carers in particular, we said, “Look, we are not getting anywhere through consultation and engagement.” So at that point—this was on 1 July—we issued a letter of claim. We said, “These are our significant concerns. We would like you to address them. You still have time to address these concerns before we have an Act and regulations.” You cannot legally challenge a Bill in Parliament; you have to wait until you have an Act and regulations. If we still felt that our concerns were unaddressed and that significant numbers of disabled people, carers and others were at risk and would be denied the promotion of equality of opportunity, and if we felt that the Department for Work and Pensions had not met that legal obligation, we could still approach judicial review. Would we like to? No. We are a very small charity, and it is a massive undertaking to challenge the Government through the courts. It is not where we want to be. We are still participating in the dialogue and consultation. We hope to see more significant improvement.

**Q171 Harriett Baldwin:** Okay, I am going to open it up to the more generic points that Paul was beginning to bring up earlier. In the context of changes from DLA to PIP, but also in terms of the Incapacity Benefit migration to ESA that is happening at the same time, what should we be saying in our report to the Department? In our previous report on ESA migration, we asked the Government to take great care to provide context on any statistical releases. The majority of people who claim Incapacity Benefit will be claiming DLA, but there will be lots of people who receive DLA who are not on Incapacity Benefit. What should we be saying in our report to try to ensure that when the Government communicate in

either of those areas that they really try to be as clear as possible? Should they put in more or less context? Do you agree that it is an area rife with potential for inaccurate reporting?

**Paul Farmer:** I think it is absolutely an area rife for inaccurate reporting: we have seen an awful lot of that already. Someone gave us an example in our consultation work about the value of DLA. The value of DLA is a message that has been totally lost in this process. There are very positive stories to be told about the way in which people are able to contribute to society with the support of the benefits system, including DLA. That side of the story is wholly lost in what appears to be a focus on fraud, error and bureaucracy. Nobody wants fraud or error and most people do not like any more bureaucracy than is absolutely necessary in the system. However, there are some significant opportunities to present a much more positive approach to the contributions that disabled people can and do make to our society.

In a broader policy context that is seeking to support people with disabilities to work, the message that the average employer currently receives about disabled people and, more broadly, people on benefits—because unfortunately those two communities are being conflated—is that these are people on the scrounge and not entitled. The message is, “Don’t employ them because they’re lazy.” I am sorry to use such strong language, but that is a message that many people tell us they receive when they try to find work. There is a huge job to do for disabled people who already experience significant barriers in finding work, which is currently not being helped by some of those messages.

There are a couple of very specific things. People in receipt of benefits are, of course, on a database within the DWP. I think there are significant opportunities to communicate with those individuals about some aspects of the process, and to be reassuring about the nature of the process. People are concerned that they are going to be reassessed immediately. I think some clarity about timeline would be helpful. People are concerned, as you have said, there are other issues happening at the same time. Some understanding about those processes and recognising the distress that this can cause, and getting that right, could be really important. There is a real opportunity here to get this process right, but if it is rushed and is insensitive to the needs of disabled people it could be badly wrong.

**Q172 Harriett Baldwin:** I have one final point on language. At the end of this process, we will have gone from a situation where someone could be labelled as on incapacity benefit with Disability Living Allowance—which seems loaded linguistically with fairly negative connotations—to having Employment and Support Allowance and Personal Independence Payment. Does that linguistic journey help in any way in terms of communication and what you aspire to for the groups that you represent?

**Amanda Batten:** It certainly could. There is a real onus on the Department when it is releasing statistics around both of those benefits, to provide more explanatory notes and context. It can inadvertently fuel quite misleading reports in the media. The kind

<sup>2</sup> National Centre for Independent Living

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of language that you used there—the names of the benefits—is not filtering through to media reports. I was struck by some research by the Strathclyde Centre for Disability Research, looking at media reporting around disability, comparing coverage in 2004–05 with the last year. It found that articles on disability benefit and fraud had doubled in that time and that there had been an increase in pejorative language around disability. I think that is filtering through, because in the focus groups that they did as part of that research, the participants thought fraud was much higher than it is around disability benefits and cited the media as evidence for that. Many people suggested things like 70% fraud levels on DLA when it is 0.5%. There is a real problem, and we have a lot of calls to our helpline from people who are quite distressed by some of the language. It has quite practical implications for people; there was one caller who had a child with autism, lived in a very rural area and relied on her neighbours for lifts. One neighbour apparently said, “I don’t know why we need to give you these lifts all the time, because you’re entitled to all this stuff—aren’t you being given a car?” That was following an article around how everyone with ADHD<sup>3</sup> gets a mobility car. I think it does have quite practical implications for people, and the DWP has a responsibility.

**Eugene Grant:** I would definitely echo Paul and Amanda’s comments. As well as the wording of the benefits themselves, which is important, what is more important is the social narrative that is in the media and that comes from Government. It is about the release not only of statistics but of case studies, because the case studies that are released dictate the story, and we know that some of these case studies come from the Department. Even though you can have a benefit like DLA, which at 0.5% fraud is much lower than some of the other non-disability-related benefits, all it takes is a statistic and a case study and suddenly you have a *Daily Mail* headline, or a headline in another publication. The fact that the Government’s objective around PIP is to ensure that disabled people are able to overcome these barriers that stop them contributing is very welcome, and that needs to be strongly communicated. The tone at the moment is quite negative, and there is lots of research from think-tanks that shows the attitudes to benefits and reciprocity is dwindling, so that needs to be combated with a very positive communications campaign.

**Geoff Fimister:** In Scotland there is a campaign called “Stick Your Labels”, which all the main political parties are signed up to. It is campaigning specifically against negative stereotyping of claimants. It would be wonderful if we could have something like that south of the border.

**Q173 Chair:** Until somebody else mentioned it down here I had never heard of it, and I am not sure whether Sheila knew about it either. So certainly you can have a campaign that does not necessarily have any resonance outwith—or even within—the political sphere. Sorry, I interrupted you.

**Neil Coyle:** One label that the Department for Work and Pensions press office and Ministers routinely use is “taxpayer”. It creates a false divide; in routine articles there is a DWP press officer quoted as saying that we need a welfare system that is fair to the taxpayer. We all agree with that, but where the barrier is drawn is almost suggesting that disabled people are not contributing at all. We talked about it today; DLA is available in work, and people who get contributory ESA have worked, so to use the narrative that disabled people do not pay tax is deeply unhelpful and comes back to the points that Paul has already made.

In terms of building trust, better communications and better information, we also have a role to play. We welcome being active participants in providing trusted information and support to individual disabled people, be it on an impairment basis or pan-disability like at Disability Alliance or Disability Rights UK. We welcome that role, but we also need some resources from DWP in order to be able to fulfil that. That was not made available under ESA for a very significant change. We hope it will be available under plans for PIP or whatever the new benefit ends up being called.

**Q174 Chair:** Before I lose the Committee completely, because the House is now sitting, can I just ask a round-up of questions on the delivery of the PIP assessments and who will carry them out? Can I just be clear what your position is? You seem to be complaining that there potentially could be too many face-to-face assessments of the same person for each of the different benefits, whether it is for social care, for DLA—or PIP, I should say—or the WCA. At the same time, I think from what Eugene is suggesting, because they are quite different benefits—part of the problem with the press is that they conflate them all as though they were all the same benefit—with, quite rightly, different criteria, you could not cut down the bureaucracy by having just one assessment for all of this. You need different kinds of assessment, but it is a case of not having them all as face-to-face assessments. Is that a fair summing up of your position?

**Neil Coyle:** We probably have most faith in one locally based assessment, be it for social care, that goes on. There are risks of that approach—lots of different risks—some being that, obviously, if it is just focused on care you are bringing in a means test, which would have to be taken out of the equation, but also that there is a risk to Government, because local authorities might then be more likely to allocate greater national resources and less local resources.

Would we, Disability Alliance—I say we, but I am not speaking for the whole panel here—prefer one assessment? Probably yes, based on the experience disabled people tell us: that they would rather agencies better shared information and that there was one assessment able to take into account in and out-of-work benefits and any social care and other support allocation.

**Eugene Grant:** I think there is definitely an appetite for reducing the number of assessments that disabled people have to go through. Bearing in mind, throughout these two hours, we have been talking quite a lot about the assessment for one benefit and the

<sup>3</sup> Attention Deficit Hyperactivity Disorder



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difficulties of that, and also the assessment for another benefit—the ESA and the WCA—that shows how tricky it is to get an assessment for one benefit right. To get a single assessment that would lead to multiple benefits would need some very careful consideration.

**Q175 Chair:** Which leads me on to the next question. We have heard the name Atos, which has become a rude word for disabled people across the country. But there must be other organisations, both in the private and public sectors or from the voluntary sector, I should say, that carry out these assessments. Are you, as organisations, either individually or collectively identifying where those organisations are or speaking to organisations that could deliver a different type of assessment—one that you would be happy with and that would not have all the flaws of the WCA that everybody universally accepts has had a really bad or rocky introduction? Are you working with any of those to find out what that kind of assessment would look like?

It would also have to be an assessment that the Government would be happy about—that would cut down on fraud or error and actually get the right amount of money to the right people—and that would deal with all the horror stories we are hearing in the paper and the case stories of even disabled people saying, “I know there are people who are fiddling the system”.

**Paul Farmer:** I suppose there are two sides to this, aren't there? One is the creation of the assessment process, whether that is the form or the questions that are asked in the face-to-face assessment. At the moment, those are determined by the commissioner, which in this case is the Department for Work and Pensions.

Within the ESA model and the WCA model, we have identified three component issues, one of which is the flaw of the process. Here, we have a really good opportunity to define that process in a different way from the way in which other processes have been approached. The second, if you are going to go down a contractual route, is around the choice of contractor, and the nature of the commission and the nature of the contract about the way in which that process is delivered.

The third area is about the quality and transparency of the deliverer itself. A lot more building into the contract and encouraging all providers to be more transparent about what is working and what is not working would help significantly. We have relied on the individual experiences of, in our case, people with mental health problems but, more broadly, people with disabilities, who have told us about their experiences of other assessment processes and have told us how difficult they found them. A greater degree of transparency between the commissioner and the provider would have identified that problem a lot earlier on.

The framing of the commission, assuming that that is the route that is gone down, is going to be really crucial. There are different providers who can deliver it in different ways, but there needs to be sufficient flexibility in the commission for that to be possible. So it is a two-sided issue.

**Geoff Fimister:** I would entirely endorse that. Those are exactly the points that I would have made. It is a question of getting the assessment process right and making sure that the people who you are paying to carry it out are doing a good job of it.

**Eugene Grant:** Ultimately, it is about what you are trying to do with the benefit. If you are trying to ensure that people who face barriers get support to overcome them, you need to contract people who understand where those barriers come from, as Jane Campbell<sup>4</sup> pointed out in her speech. Therefore you will need to contract an organisation, or at least a group of professionals, that will have a broad understanding of that, not necessarily just medical examiners.

**Amanda Batten:** That is perhaps where organisations such as ours can give support. Our experience of public service contracting indicates that the contract for this would go to a provider that has a national scale on the same sort of lines as Atos. Our organisation and local organisations can help in terms of providing training and support for those providers, because, as a big, homogenous, national contractor, having the expertise and training to be able to differentiate those assessments and communicate with such a wide group of disabled people will be a real challenge.

**Q176 Chair:** Ultimately, any assessment process will say “No” to some people.

**Amanda Batten:** Yes.

**Q177 Chair:** And those will be the people who are unhappy. For them, the assessment process has not been good, because it has said “No”. At the moment, we still have 40% of those going off to appeal and 40% are winning, and that is not good. I think that somebody talked about getting the assessment right the first time. Are the Government not suspicious that your organisations would try to widen the criteria to include too many people, which obviously has implications for the public purse?

**Amanda Batten:** I do not think so. I think that it is about ensuring that the assessment is fair for everybody. If you have a face-to-face assessment with someone with autism who, because of the impairment in their social imagination, does not necessarily have insight into their own needs or is unable to communicate the barriers that they face, that person is put at a disadvantage if the assessment just relies on them being able to do that. It is about making sure that the assessment is adapted, so that disabled people can give an accurate and clear account of the difficulties that they face.

**Geoff Fimister:** We see the process going in the opposite direction, and I try to resist this, essentially. On the ESA point, you see people found fit for work when they realistically are not going to get a job, and the implications for them are serious. The debate is often conducted as if it is a question of people being got off out-of-work benefits and into work, and that is not what is happening. There are three bits to it. You are first precipitated on to much lower rates of benefit

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<sup>4</sup> Baroness Campbell of Surbiton (in the House of Lords debate on the Welfare Reform Bill.)

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or, if, for example, you are moved from a contributory to a means-tested benefit and you have a working partner, potentially no benefit at all. Although we are entirely in favour of people being given opportunities to work—that is tremendous—we are not in favour of people simply being shunted on to much lower levels of benefit.

**Eugene Grant:** We are not necessarily saying at all that you need to expand the caseload. We are just saying that if you get the assessment right, you ensure that you have the right caseload. If you have the

assessment right, it could be higher or lower. You do not know until you have a fit-for-purpose assessment and then roll it out through a very careful process.

**Chair:** I think that we could have gone on for much longer. We always get bogged down in the first section. Thank you for coming along this morning. If you feel that there is something that we have not covered and you have a burning desire to write to the Committee, please do, because any written evidence will be included with the oral evidence you gave this morning.

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**Monday 12 December 2011**

Members present:

Dame Anne Begg, in the Chair

Harriett Baldwin  
Karen Bradley  
Sheila Gilmore

Stephen Lloyd  
Teresa Pearce

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**Examination of Witnesses**

*Witnesses:* **Maria Miller MP**, Minister for Disabled People, **Dr James Bolton**, Deputy Chief Medical Adviser, and **Simon Dawson**, Deputy Director, Independent Living and Office for Disability Issues, Department for Work and Pensions, gave evidence.

**Q178 Chair:** Minister, thank you very much for coming along this afternoon. Something exciting is happening in the Chamber this afternoon, and some Members are still there trying to catch the Speaker's eye. Perhaps that helps to explain why we are slightly thinner on the ground than we might have been, but thank you very much for coming along anyway. I understand that you have a very brief opening statement to make.

**Maria Miller:** Thank you, Dame Anne. I would like to thank the Committee for the opportunity for my colleagues and me to come along today to discuss Disability Living Allowance (DLA) reform. We remain committed to supporting disabled people and focusing on helping those who experience the biggest barriers to leading an independent life. Across Government we spend some £40 billion a year to provide support and services for disabled people. DLA is one of the most important ways we support disabled people, and we feel that it is no longer working in the way it should. You have heard evidence from others to that effect. The eligibility criteria are outdated, reflecting society's understanding of disability of some two decades ago; awards are inconsistent, and therefore can lack credibility. Of those cases that go to appeal, some 40% of decisions are overturned. This has damaged people's confidence in the system. There is also a high number of nugatory claims. Less than 45% of DLA claims are successful, and we feel there is over-reliance on a very complex self-assessment questionnaire with no systematic review of benefits built into the system, with awards becoming therefore inaccurate as changes in circumstances are not routinely picked up.

The Personal Independence Payment (PIP) has been developed with independent health, social care and disability experts to take better account of modern views on disability, including cognitive, mental and sensory impairments. We feel the new assessment is fairer, as it focuses on needs that have arisen as a result of a condition. It is more consistent, as the criteria are more clearly defined, and more objective, as individuals have had the opportunity to talk to a health professional about their condition and how it impacts on their day-to-day life.

We will make sure that people receive the right level of support through a personalised approach, and more active, systematic reviews based on the likelihood of their health condition or impairment changing. Most

importantly, we will ensure that we continue to involve disabled people in the design and implementation of this important new benefit.

**Q179 Chair:** Thank you very much. In all of that you have not mentioned money at all, and yet one of the major reasons the Government have given for changing DLA and introducing PIP was to cut 20% of the DLA budget. What evidence do you have that increased DLA expenditure and caseload is due to a widening interpretation of the eligibility criteria, or how much of it is due to a growing awareness that the benefit exists, or demographic changes?

**Maria Miller:** I think I should set out from the start that the reform we are undertaking here is very much a principled one. We are all aware of the statement of the Chancellor. How we undertake that reform of Disability Living Allowance and the introduction of the Personal Independence Payment is absolutely rooted in making sure we have a benefit of integrity, and it has behind it principles that will deliver good support for disabled people. To us, there is very clear evidence that there are problems within the system as it currently stands. We know from research carried out in 2004–05 under the National Benefit Review that there were significant problems with incorrect awards. There were some £630 million of overpayments, and the figure for those people not receiving enough support was £190 million. There is evidence there of inaccuracy within the system.

With regard to people who claim the benefit and their awareness, the fact that we get such high levels of nugatory claims—almost half of the claims we get are from those who do not have basic eligibility—suggests that the problem is not necessarily that people don't know about the benefit but that they are coming forward without the required eligibility.

**Q180 Chair:** But that confuses me, because that means they don't get it. The criteria must be quite tight if a large number of people who apply don't get it, so why bring in a completely new benefit with new criteria in order to cut down on the caseload?

**Maria Miller:** It is about basic eligibility, as opposed to an assessment of more detailed needs. I don't know whether Simon wants to comment on that.

**Simon Dawson:** My name is Simon Dawson, and I am Deputy Director with responsibility for Personal Independence Payment and DLA policy. To add to what the Minister said, only one third of the growth

in DLA in the last eight years can be attributed to what might be called demographic factors, the remainder being accounted for by average receipts per head.

**Q181 Chair:** To stop you there, your Department still published the statistic of an increase of 30% in those claiming DLA, and that was used as a justification for getting rid of it completely and bringing in PIP instead.

**Simon Dawson:** We would argue that the current benefit is not very well understood. People don't understand when they might not be entitled.

**Q182 Chair:** The Minister has been very clear that it is not well understood. My question is: how can it be better understood when you bring in something new? Possibly one of the reasons why the caseload of DLA has gone up is that it is now better understood 20 years on—more people know about it. We have questions on that. The original statistic used was that the caseload of those applying for and receiving DLA had gone up by 30%. You have just said that a third of that was probably due to demographic changes. The move from DLA to PIP will not remove those demographic changes, unless you say that PIP will not continue after the age of 65. I understand that is not the case. Is that true?

**Simon Dawson:** It is true.<sup>1</sup>

**Q183 Chair:** Therefore, those demographic changes will continue and that proportion will increase. Some of the increase was because of demographics. That is not taken out by the move to a new benefit. Some of it is the result of a better understanding of the benefit, but in that case the new benefit might do that because people won't know about it. I don't want to get into that, because I know we have questions on it. The question I am asking is: what evidence do you have that the increase in the uptake of the benefit has anything whatsoever to do with a loosening of the criteria?

**Simon Dawson:** The fact that the growth in caseload itself has broadened the eligibility criteria—

**Q184 Chair:** But that has brought in people, perhaps the blind and others, who did not get it before, but are you saying that the groups that have been taken into the criteria for DLA in recent years will be automatically excluded from PIP?

**Simon Dawson:** No. The National Benefit Review statistics show that about £630 million of expenditure is accounted for by unreported changes of circumstances due to people's conditions changing, which clearly suggests something about a loosening of the criteria.

**Q185 Chair:** Surely, the answer to that was to put some periodic reviews into DLA.

**Maria Miller:** At this point I think it is important to restate the case for change here. At the risk of making

<sup>1</sup> Individuals in receipt of Personal Independence Payment would continue to be entitled beyond age 65 so long as they continue to satisfy the eligibility criteria. This age-limit will increase in line with the changes to State Pension age.

a very simplistic statement, if it was as easy as making some small changes to DLA then the previous Administration would have undertaken that. A lot of the changes we have been looking at in trying to bring the assessment into the 21st Century, and making sure we have a tighter gateway into the assessment so there is more certainty that those with the greatest need are receiving it, require us to look at a new legislative structure. It is very difficult to achieve those sorts of changes under the current DLA, because so much of the detail of the Bill is enshrined in primary legislation. I can perhaps understand why it was done at the time, but it has meant a real lack of flexibility within DLA to adapt to changes. We know that from the problems to do with the blind and the measure that had to be the subject of primary legislation.

The answer to your question is that there is absolutely a need to reform the benefit very fundamentally; that there is clear evidence to suggest that only a third of the growth over the last eight years—it is, I think, 38%<sup>2</sup> growth—can be attributed to demographic factors; and the remainder will be linked to the problems of the slippage in gateway. The fact that half of the people who apply for DLA—55%—are rejected at stage one tends to suggest that lack of knowledge about DLA is not necessarily a problem across the board.<sup>3</sup>

**Q186 Chair:** Do you not accept that it might be a good thing if the caseload of DLA has gone up because more people know about it and therefore more people are applying, which may explain why you have a larger number being rejected at the first stage? Again, that is not a good reason for sweeping away all of the existing benefit and replacing it with something new.

**Maria Miller:** For clarity, we are not sweeping away the support that is available but putting in place a very modern approach to supporting disabled people, which has been designed working directly with disabled people and their organisations right from the start. I am not sure I agree it is a good thing to have so many people who don't have basic eligibility applying, because there is a cost associated with looking at each assessment form. You will always have a level of misunderstanding about what a benefit is, and some people who apply do not have eligibility, but to have this scale of problem is something the Committee should be concerned about. It shows a basic lack of understanding, or perhaps a feeling that there is such a vague notion of who is eligible for DLA that many will apply just to see whether they are eligible, and perhaps that is not something the Committee should be satisfied about.

**Chair:** We have questions about how the Treasury managed to arrive at its 20% figure.

**Q187 Sheila Gilmore:** One of the habits of politicians is to say that we need to modernise things

<sup>2</sup> This refers to an increase in overall Disability Living Allowance spending in real terms from 2002–03 to 2010–11 (2011–12 prices).

<sup>3</sup> DWP, *Analysis of Disability Living Allowance: Awards*, March 2011: [http://dwp.gov.uk/asd/asd1/adhoc\\_analysis/2011/analysis\\_of\\_disability\\_living\\_allowance\\_DLA\\_awards.pdf](http://dwp.gov.uk/asd/asd1/adhoc_analysis/2011/analysis_of_disability_living_allowance_DLA_awards.pdf)

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without putting any content into it. You have talked today and on previous occasions about bringing the benefit into the 21st Century. Can you give some examples of what you mean by that?

**Maria Miller:** These are things that were touched on by organisations that have given evidence to the Committee previously. One particular area I give as an example is the current problem with Disability Living Allowance, fully recognising the problems of mobility faced by people with severe learning difficulties. The higher rate Disability Living Allowance is very focused on individuals who have a physical impairment, and I think it is widely accepted that it is less able to deal adequately with the real needs of people with a learning difficulty or mental health problems. We experienced some of the limitations of the structure of the DLA primary legislation when changes were made to do with the blind or those with severe visual impairments.

First, in terms of modernising, this is a benefit on a very practical level that recognises the real needs of people with learning difficulties, but second, it is modernising the structure within which the legislation operates so it is more flexible to accommodate changes over time. I am sure the Committee would agree with me that our understanding of disability and how we can support disabled people is evolving over time, and it is something I am hoping to look at in more detail as part of the disability strategy that the Government are undertaking at the moment. I don't know whether Dr Bolton wants to add anything to that.

**Dr Bolton:** My name is James Bolton. I am the Department's Deputy Chief Medical Adviser. I have been leading on the development of the assessment. There are a number of ways in which, as we have gone through the current criteria for DLA, we have looked at ways to modernise them. We have been working with a group of independent people representing health, disability and social care and also with disabled people and representatives of disabled people's organisations. That group has been working in a co-produced way to look at the existing DLA criteria. They were allowed to start with basically a blank sheet of paper and come up with ways they think it could be better. That is where the assessment criteria of PIP have evolved from. We have already heard the example of how Disability Living Allowance, particularly if you look at higher mobility, focuses on individuals with physical health conditions, yet for individuals with mental health problems the barriers in terms of what they can do and their ability to get out may be very similar. Those are the sorts of things we are looking to address.

Another example of what we have been looking at is that DLA is very focused on care and mobility, which are the criteria in primary legislation. We have had representation from various disabled people's groups on things like communication, which is something DLA does not look at. What we have come forward with in our proposals is quite a complex scheme that looks not just at how an individual is able to communicate and what may be the barriers and costs associated with that but also social engagement, so there is also a nuance to some of the barriers to

communication that can be created. What we have brought forward in our proposals, which we are co-producing and working on in a very consultative way, is much more holistic and broader than Disability Living Allowance. The other advantage of being able to specify this in regulation is to allow us a lot more flexibility. As part of the Welfare Reform Bill we have a review built into the process, and this is something we can keep constantly under review. As things change we have the flexibility to update it and reflect modern views and changes in society and medical care.

**Q188 Sheila Gilmore:** I have some difficulty in understanding where we are going with this. I don't think anybody would say you should not have criteria that are more holistic and broader, and the examples the Minister has given are quite helpful. Clearly, if those are not covered by DLA currently and yet they give people a problem in engaging in their social or working environment, or whatever it is, we want to include that. That would suggest the new criteria and benefit will cover more rather than less people, against the backdrop from the outset of a forecast reduction in expenditure of 20%. How was that arrived at?

**Maria Miller:** As to the number of people who will be in receipt of the benefit, we have not yet finalised all of the assessment. The Committee will be aware that we published a revised set of assessment criteria with a weighting associated with it, but we have not finalised all of that and so we are not yet able to give you complete details as to who will receive the benefit in future. Keeping that in mind, what we have been trying to do throughout this process is take a fundamental look at who most needs support to live an independent life.

**Q189 Chair:** I am sorry, Minister. I am conscious of the time. We understand all that, but the question Sheila Gilmore asked was: given all of that, where did the 20% figure come from? If you don't know the number who will qualify for the benefit, how could the Treasury say there would be a saving of 20%?

**Maria Miller:** I said right from the start that our starting point is a principled reform.

**Q190 Chair:** But that flies in the face of a flat 20% off the DLA budget.

**Maria Miller:** The Treasury looked at the Work Capability Assessment (WCA), which suggested that introducing a face-to-face assessment would reduce expenditure on DLA by about 20%. In response to the challenge from the Chancellor, we said we wanted to take a fundamental and principled look at DLA. It is not the first time the Government have done this; perhaps it has been done in the past, but we thought this was a great opportunity to be able to modernise a really important part of the support system for disabled people.

**Q191 Sheila Gilmore:** Therefore, you still have a savings target of 20%?

**Maria Miller:** Members of the Committee will be aware of what is in the Budget, and as Ministers in a Government that has inherited one of the worst budget

deficits in recent years we have to make sure that the support we offer to some of the most vulnerable people in our community is sustainable in future. I think people would expect us to do that.

**Q192 Sheila Gilmore:** If you are to extend the new benefit to people who hitherto have failed to qualify because the criteria did not match them, are not a good number of the organisations who have given us evidence right to suppose that a lot of people will lose benefit altogether as a result of the changes you are proposing?

**Maria Miller:** I would urge the Committee to look at the figures and facts. The facts are that, at the end of the Spending Review period, we will be continuing to spend the same on PIP as we did last year on DLA. That is after eight years of significant increases amounting to around 30%,<sup>4</sup> two-thirds of which is not to do with demographics. Therefore, rather than put in place a very different regime in which to operate, we will be operating with the same budgets in 2015 as we did in the last fiscal year. I think that would give the Committee some confidence that what we are trying to do is to keep that rate of increase more in line not only with what the country can afford at this time but also with the fact that we are not seeing an increased incidence of disability in our communities.

**Q193 Sheila Gilmore:** I presume you are assuming that the current rate of inflation will rapidly reduce; otherwise, in real terms spending will be considerably less than it was last year. Aside from that, are you not really still saying, if you want to take on new people, as well as holding down expenditure—presumably, there will be some inflation—that a number of people will no longer get a benefit? Do you have any assessment of what those numbers are in reaching your financial conclusions?

**Maria Miller:** As I said earlier, we have not finalised our figures because we have not finished the assessment yet; we are still working with disabled people and their organisations, and it would be wrong for me to prejudice that. You are right to say that there are tough choices to be made and I do not shy away from that, but what we are trying to do is make sure those are fair choices and that there is consistency in the way the benefit works in future, in the way there has not been in the past. You may agree that inconsistency itself is not fair to disabled people if individuals with similar conditions may or may not get the benefit support they need because of problems to do with a self-completion questionnaire, which is perhaps as good as the person who helps you fill it in. That is no way for us to run a £12 billion benefit—one of the biggest we have in this country—with a budget that is larger than the entirety of the Department for Transport.

**Q194 Sheila Gilmore:** Some of my colleagues may want to ask whether or not it is just a question of people filling in the form. There is quite a lot of dispute as to whether it is fair to say that is all that

goes on here. As to the financial position, a lot of people were very pleased to see you have changed your mind about the removal of mobility allowance from people in residential homes, which is something people have campaigned against from the time it was proposed. That also had a savings implication because a reduction of some £160 million was in the financial estimates. Is your Department still expecting to find additional savings from the migration from DLA to PIP that now will not be found from removing mobility allowance from people in residential care?

**Maria Miller:** As you would expect me to say, the Department has very clear commitments to the Treasury in terms of the spending it is able to undertake in the spending review period. The answer to that question is, very firmly, that we will have to find the funding that was associated with the mobility component for people living in residential care, but we will not find it from within the Disability Living Allowance.

**Q195 Sheila Gilmore:** From within PIP?

**Maria Miller:** Yes.

**Q196 Sheila Gilmore:** So, it will be found from elsewhere in the Department's budget?

**Maria Miller:** From the wider Department budget, and, as I am sure you are aware, that is a very sizeable amount of money; it is £158 billion in total.

**Q197 Stephen Lloyd:** What was the Department's rationale for not retaining DLA but having face-to-face assessments? Obviously, it costs a considerable sum of money to transfer and bring in something completely different. I think most fair-minded people recognise that DLA needed a level of face-to-face assessment rather than paper, with some possible exceptions for very specific disabilities. Maybe one way we could have saved a few hundred million pounds was to retain DLA and have face-to-face assessments. Why was that never really considered?

**Maria Miller:** I will defer to Simon Dawson in a moment because he has a lot more of the detail on this than I have. It was considered. All options as to how we could make sure that the support we gave to disabled people was delivered in the most effective and cost-efficient manner were considered. There is a very strong case to be made that it would be impossible to deliver that within the framework of Disability Living Allowance because of the structure of the primary legislation. So much of the structure of the benefit is enshrined in primary legislation rather than regulations. Therefore, the ability to make those changes, which perhaps to you and I would seem very obvious things to do, would require changes in primary legislation, which led us very clearly to the need to move to a new benefit, not only in terms of the face-to-face assessment but the fact there is no inbuilt, systematic review either. To make those sorts of changes was very difficult within the structure of DLA. Perhaps Simon wants to come in.

**Q198 Stephen Lloyd:** Before he does so, I hope the new legislation includes a certain amount of flexibility so that if, in a few years' time, whichever Government

<sup>4</sup> This refers to the growth in the number of claimants on Disability Living Allowance between 2002–03 and 2010–11.

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is in charge—hopefully, the Coalition or whatever—wants to change something again, it does not have to go down the route of primary legislation. That happens so often and is fantastically inefficient and very difficult for many disabled people.

**Maria Miller:** You are absolutely right, and we are structuring the new benefit to give us that flexibility in future.

**Simon Dawson:** To add to what the Minister has said, the cost of introducing more systematic, or face-to-face assessments, into the existing DLA, along with the associated IT, training and communication changes, would not have been far short of the cost of introducing a new benefit in its entirety. For example, the cost of the assessment would be about one-fifth of the overall cost of implementing the Personal Independence Payment, so introducing the sorts of changes that other witnesses have described into DLA would have resulted in, broadly speaking, the same sorts of costs as for Personal Independence Payment.

**Q199 Stephen Lloyd:** Moving on, I want to look at assessing the impacts of the reform. A number of disability organisations have been concerned that the change to two rates of the PIP daily living component, rather than the three of DLA care, will result in the current 650,000 working age lower rate DLA recipients losing support. I am sure you appreciate the anxieties there. Minister, you have said that this is simply speculation but, as I understand it, as yet we do not have a clear response from you as to exactly who is likely to lose out.

**Maria Miller:** I think the important point is that the reform we are putting in place is not as simple as removing the lower rate of DLA. The new assessment criteria are a more fundamental reform of the way we are supporting disabled people. The number of individuals who will benefit from that and those who will see changes to their awards will be forthcoming in the next few weeks as we finalise the assessment criteria and their weightings in discussions with disabled people and their organisations, and then put in place thresholds. Therefore, I cannot directly answer that question today.

**Q200 Stephen Lloyd:** I understand. Once you have made an assessment of what you think those numbers are, I would be very grateful if the Select Committee could get some information from you about the number of people you believe are involved. That would be very helpful.

**Maria Miller:** Perhaps I may reassure Mr Lloyd that is exactly the work that will be ongoing as soon as those assessments are finalised. Indeed, we have given a very clear undertaking to their Lordships in the other place that that information will be available prior to debate of this stage of the Bill in the Lords. That will be forthcoming shortly, and I am sure it will be helpful for the Committee to see that. I am sure officials will ensure that information is forwarded to you.<sup>5</sup>

**Q201 Stephen Lloyd:** Thank you for that. Many of the people who will be affected by DLA reform will also be affected by the Incapacity Benefit

reassessment. What assessment has the Department made of the cumulative impact of IB and DLA reform on the capacity of disabled benefit claimants to meet their living expenses?

**Maria Miller:** This is something of which we are very conscious. There are many different changes being undertaken. We are mindful of the fact that, whether it is disabled or non-disabled people, there will be overlaps in terms of the impacts of these changes. That is something we are looking at very closely. When we have finalised the impact of the changes to DLA through the introduction of PIP we will be looking at that, but until we have finalised that it is difficult to provide a direct answer to your question. I reassure you that that is something of which we are very mindful. Of course, there are also some practical issues around that.

**Q202 Stephen Lloyd:** The next thing that slightly surprises me, from my own constituency casework, is that you and the DWP have rejected the argument that these reforms will have knock-on impacts on the NHS and social care budgets. In your judgment, does not DLA play any preventative role in this respect?

**Maria Miller:** You ask two different questions. One is whether or not the changes will have any direct effect on the amount of money people have to support themselves, and the other is whether there is a preventative effect. I am sure DLA, and soon to be PIP, has a very clear role in helping people continue to live an independent life both through working age and beyond retirement as well. From speaking to people who are recipients of DLA, that is absolutely the case. To reassure you, I see that continuing in future, but there are some issues about local authorities' ability to take into account DLA. I don't know whether Simon wants to comment on that.

**Simon Dawson:** As the Committee is probably aware, local authorities have always been able to charge against receipt of someone's disability-related income, including the DLA care component, if they are receiving local authority-provided social care support. Equally, some local authorities choose not to do that, and where the benefits are taken into account councils should be guided by the overriding principle that charges do not reduce the user's net income below basic levels of income support plus 25%, and do not result in the user being left without the means to pay for any other necessary care, support or other costs arising from their disability. Obviously, that will continue going forward.

**Q203 Stephen Lloyd:** Presumably, the DWP is liaising with the Department for Communities and Local Government (DCLG) and the Department of Health, because clearly there will be occasions when they will impact either on the local health service or local authority.

**Simon Dawson:** Both the Department of Health and DCLG are members of the cross-Whitehall personal independence working group set up last year—there was a meeting of it today—to discuss issues related to the interaction between DLA or Personal Independence Payment and other services provided to

<sup>5</sup> Ev 111, also see: [www.dwp.gov.uk/pip](http://www.dwp.gov.uk/pip)

disabled people, including passported benefits sponsored by other Government Departments.

**Q204 Sheila Gilmore:** If people who currently have social care lose eligibility for benefit, and that benefit is properly taken into account in assessing their fees, with all the safeguards you have suggested, is there not a knock-on consequence to local authority budgets?

**Maria Miller:** If an individual was deemed not to be eligible for the Personal Independence Payment, it would be because they would not have the need for that level of support, so by definition it would mean that individual was not in need of that level of support.

**Q205 Chair:** But it is a different assessment. The council will have gone in and done its assessment and assessed the person as needing X level of support. Today, that person probably has DLA care and uses it to pay for the council-provided care. If they don't qualify for the new PIP, the council may still assess them as needing that care.

**Maria Miller:** The individuals who would be in need of that level of care would be assessed under the Personal Independence Payment as needing a level of care to remain living an independent life.

**Q206 Chair:** But it is a different assessment. The point is that the assessment you make in order to qualify for PIP is not the same as the assessment that a care manager will make of an individual in the community.

**Maria Miller:** The use of DLA, or in future PIP, is a way of assessing individuals, not just through social care but things like blue badges. People have used eligibility for DLA as denoting some level of care and need for support. That is for individual departments to consider.

**Q207 Stephen Lloyd:** I will give you the example of a case I am dealing with at the minute. A constituent had a wet room installed because her husband is on higher rate mobility DLA. For instance, if a few years down the line, for whatever reason, someone in that situation loses DLA, does it mean that the local authority removes the wet room, to give a slightly hyperbolic example? The real point we are looking at is that there will be changes and some people will lose. Presumably, there will be a system that then allows the local authority to reassess it, and remove the funds or make up the difference. That is where your conversations with DCLG will be very important.

**Maria Miller:** You are absolutely right—it is important that all of these knock-on effects are fully taken into account. That is why, as Simon Dawson has already outlined, we have a cross-Government group looking at these issues. It really is up to other Departments how they look at eligibility for benefits as a way for pegging eligibility for funding streams they may offer. Disability facilities grants are an area where the Government has increased expenditure, as I am sure Mr Lloyd is aware, and it is something to which we are very committed. It is for DCLG working

with local authorities to look at eligibility for that income stream.

**Q208 Chair:** But they won't get the facilities grant if, as a result of your changing the criteria that allow them to get PIP, they no longer get the equivalent of the higher rate mobility DLA. The wet room is a good example, because the criteria change. Someone who is a very active self-propelled wheelchair user needs a wet room in the same way that someone with profound disabilities needs a wet room, but one will get the 15 points and the higher rate because they have profound disabilities and the active wheelchair user does not, but both still need the wet room. You cannot say that passporting the benefits is up to other Departments. If you are changing the criteria on which they base a lot of their decisions, which saves them money because they do not have to reassess continually, surely that is of huge concern to your Department.

**Dr Bolton:** One of the things we have done within the assessment is recognise that individuals with wheelchairs will have significant extra costs. There are a number of points associated with requiring wheelchairs. I don't think the example of the person who can walk and the person who cannot and is in a wheelchair necessarily works.

**Q209 Chair:** The active wheelchair user will get only 12 points. Will 12 points be the equivalent of the higher rate mobility DLA?

**Dr Bolton:** We have made no decisions yet about what the entitlement thresholds are, because we are continuing to work with disabled people and their groups on the weightings to be applied.

**Q210 Chair:** But this person does not get the wet room if that is not so.

**Dr Bolton:** To go back to the Minister's earlier point, the key is that individuals with a level of disability we can recognise within the assessment will continue to receive PIP at either the standard or the enhanced rate. That is the key thing about it. The people who will not be receiving PIP are individuals who either have got better or, if they are new claimants, just do not meet the eligibility criteria in the first place.

**Q211 Stephen Lloyd:** I hear that. What we are saying—I am sure you are hearing us—is that there needs to be some very close integration on this; otherwise, there will be unintended consequences.

**Maria Miller:** To address that point directly, this is why we are working extremely closely with individuals in other Departments. I have had a meeting at ministerial level on this very issue as well. Passporting is an extremely important issue not just for disabled people but many other groups. I underline the point that it is for other Departments that may provide support to consider whether PIP is the right gateway to the support they offer in the future. There are clear examples, particularly if you look at the blue badge, where it is not just through entitlement to DLA that individuals receive a blue badge; there are other statutory measures, and local interpretation that can



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be put in place to guide the award of that particular very important passported benefit for disabled people.

**Q212 Stephen Lloyd:** One area where I have a lot of concern, which is shared by a number of different disability groups, is the qualifying period. Currently, there is a qualifying period of three months, with the extension to six months for the prospective test, and we are looking to move the qualifying period to six months. I have real concerns about people with fluctuating conditions, or even cancer for that matter. I know a number of different disability groups have made application to the DWP. They understand where you are coming from, but rather than changing from a three-month to a six-month qualifying period, which could be a long time for someone with a sudden onset illness, why not compromise by sticking with the three months but having the prospective test and stretching that out to nine months? My first question is: does the Minister accept that, when you have a sudden onset illness, six months before you can receive any DLA is a long time, and not a lot of people have six months' money in the bank, to be perfectly honest? Second, what is the Minister's view about the possible compromise of extending the prospective to nine months rather than six, but retaining three months?

**Maria Miller:** I would like to underline the fact that we have been meeting and listening very carefully to the concerns of a wide range of organisations on this issue at both official and ministerial level. My noble friend Lord Freud has also listened very carefully to the concerns raised in the other place about this. For the clarity of the Committee, it is important we remember that DLA, and in the future PIP, is there to support people with long-term conditions. I think there is general agreement that it is there to support people who have a disability that will last for 12 months or longer.

As he rightly says, the issue for individuals who have a sudden onset illness is how to get the balance right. Obviously, we have means-tested benefits to support people in the very short term who might find it very difficult financially. We want to make sure we retain the integrity of the benefit and it is there to support people who have long-term conditions. As I am sure Dr Bolton would want to say, it can be very difficult to understand the full impact, or perhaps ongoing impact, of a condition in the initial period, and there needs to be a period in which that condition can settle down. With stroke, for instance, for the first few months the individual may be in a very different situation from six to 12 months later, so we have to make sure we get the right balance between putting awards in place in a timely manner and the time when an individual really does understand the true impact of the condition on their day-to-day life.

**Dr Bolton:** Probably there is not a lot I can add to that. Stroke is a very good example. The first few months are often very critical; individuals can be in hospital for that period of time, having intensive investigations, rehabilitation, treatment and so on. The clear picture in many cases can be quite difficult to know early on. One of the other things we know from DLA is that many individuals tend to claim quite late

on for their condition; they often do not claim at the start.

**Maria Miller:** For completeness, the Committee will be aware that we are minded to take forward the provisions within Disability Living Allowance to make sure there is immediate access for individuals who are terminally ill. We would make sure that was the same in the future.

**Q213 Stephen Lloyd:** Does not the proposal of extending the prospective test to nine months cover stroke?

**Maria Miller:** You make a very important point. We have to get that balance right. We are continuing to look at the detail and, as the debate progresses in the Lords, we will continue to make sure we get the balance right.

**Q214 Stephen Lloyd:** I appreciate that you are continuing to look at it. Though I do understand part of the rationale of the DWP, the CAB<sup>6</sup> has come up with what I think is a rational compromise for extending the prospective test to nine months. I congratulate the Minister on listening to the concerns about the mobility component of DLA in residential centres and care homes and revisiting it. I am grateful for that. The Minister knows that I and others have lobbied on that frequently over the last few months. However, I want to ask about one matter that caused an awful lot of concern. Why did the DWP not do the research before the decision was taken because, as you said last week, the evidence of the overlap in funding is patchy at best?

**Maria Miller:** I understand the point you make absolutely. I would also like to pay tribute to the work Lord Low has done in this area, which has helped to improve people's understanding, on top of the work that the Department has done. As I have said from the beginning, there is a very clear theoretical overlap in the payments made in social care and DLA mobility for individuals in care homes.

The intention to make the change was made known in October of last year, and, as soon as we started to hear the very real concerns of people on the ground, we looked immediately at what was happening in practice. That is where my comment about patchy practice on the ground comes from. We acted on that very quickly to provide reassurance to people that we would be looking at that in more detail. When we said in February that we would not remove the mobility component of DLA from October 2012, we also said we would look at the practice on the ground. We have spent the time since then looking at the very different ways that local authorities deal with this measure. What I did not want to do was pre-empt any recommendations or thoughts coming from Lord Low, so it was absolutely right that we waited for his report before we made any further comment on that. I agree with him that it would not be the ideal order in which to do it, but, given the necessities of a new government, that is where we were.

**Q215 Teresa Pearce:** Minister, I was going to ask why the Department believed it was necessary for

<sup>6</sup> Citizen's Advice

most individuals to have face-to-face assessments, but in an earlier answer you said that experience of the Work Capability Assessment had led the Department to the conclusion that such assessment would reduce the DLA spend by 20%. Is the reason why most individuals will have face-to-face assessments just to reduce the budget?

**Maria Miller:** No. That was I believe the rationale put forward by the Treasury. My rationale is that I want to make sure disabled people have the right to be able to talk to somebody about their condition. Many, if not most, disabled people have more than one condition with which they are dealing. To be able to sit down and discuss that face to face with a health professional, and talk about the impact it has on day-to-day life, is a very valuable part of the new PIP assessment process. But it is only part of the new assessment process, because there will also be an application and an ability for people to be able to give professional evidence of the impact of the condition on day-to-day living. I believe it is important for disabled people to have that face-to-face assessment, but it is only part of the assessment process.

**Dr Bolton:** Over the summer we did some testing of the assessment criteria. One of the things it involved was G4S going out to do face-to-face assessments and gather information for us. At the end of that they did a survey; they sent out a questionnaire to the individual. Of those that came back, 92% were very positive. We had comments like, "It was very helpful to have someone who understood what I was explaining, such as the medical terminology and how certain symptoms affect my lifestyle as well as physically and mentally." We have a whole number of things like that. Huge numbers of people found this very positive and useful; they could tell their story and had a chance to show and explain. All of these were carried out in individuals' homes, so the assessors were also able to see the kind of adaptations and changes that disabled people needed and were able to gather a very useful amount of information as well to help inform our development and testing.

**Maria Miller:** Indeed, I think it came out in previous evidence to this Committee that sometimes people find the very negative nature of the current DLA assessment form a very difficult thing to deal with, looking at their own condition in a very negative way, and to be able to discuss their condition with a professional will be incredibly beneficial.

**Q216 Teresa Pearce:** I am interested in what Dr Bolton just said, because that description of the process is not something that this Committee would recognise from the Work Capability Assessment. As we all acknowledge, the Work Capability Assessment had significant flaws, and yet the PIP assessment is designed along very similar lines. The lines you have just described are not the same as the work capability assessment. Can you tell me how much it will differ? One of the main problems under the work capability assessment was that they may be before a health professional but that health professional would have no experience whatsoever of the condition, whereas what you have just described is almost like matching

the professional to the condition. Would that be possible?

**Dr Bolton:** In the testing we did we used predominantly occupational therapists. We don't use occupational therapists for the work capability assessments. They have a skill set that has been very well adapted to this, and we gave them specific extra training on a number of conditions as well. Regarding the Work Capability Assessment (WCA), we have been very grateful to Professor Harrington. We have now had two independent reviews from him. His first highlighted that the WCA was the right assessment and it was not broken, but he did highlight that it was impersonal and mechanistic, and he put in a whole number of suggestions for us to help improve it around better communication, explaining things, improving the empowerment of decisions makers and so on. All of those things we have done. In his second independent review, published the other week, he noticed that things had noticeably changed for the better and came up with a series of further suggestions, such as more internal communications between decision makers and the work programme, engaging representative groups, greater auditing and so on.

The key point is that Harrington has shown us so much in both of his independent reviews. We have established an implementation development group that involves disabled people and their organisations to look at how we set up PIP and make it work. Central to all of that are the lessons we have already learned from Harrington. Therefore, when you talk about the WCA and doing something different on PIP, yes, absolutely. We are already doing something different on WCA, and it is important we learn all the lessons from it and do something different in PIP as well.

**Q217 Stephen Lloyd:** Are you stating absolutely that the improvements and changes that have happened last year in the WCA will be carried over into PIP? That is very important. There have been some improvements, but they have to be carried over.

**Maria Miller:** We are making sure that any relevant learning from the WCA is carried forward to PIP. Officials are very close to both projects, so that will be absolutely critical. It is also worth underlining for Ms Pearce that there is a fundamental difference between the WCA and the PIP assessment. The former is about whether you can work; the latter is based very much on a social model approach, which is, "What are the barriers to your living an independent life?" and using the assessment criteria as proxies for that assessment process. There are some fundamental differences but some learning that is common to both, particularly the point Ms Pearce raises about the importance of training those people and access to expertise for those who are undertaking the assessment.

**Q218 Teresa Pearce:** That is an interesting point, and that is why I am concerned the Treasury has come to the decision that it can reduce the budget by 20%. If the PIP assessment works correctly you might increase the budget, but that is a separate point.

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Organisations like Sense and the RNIB are concerned that the descriptions used at the moment for people who will go to face-to-face assessments mean that it will apply to most individuals, whereas they believe there are certain conditions, such as blindness or deafness, that will not get better and would not need those face-to-face assessments. A parent came to the Committee's public meeting in South Wales. She talked about her 22-year-old autistic son who required observation over a two-week period to be assessed, so a short face-to-face interview would not achieve anything in those circumstances. Is there any chance that you will be looking at various conditions so people will not have to go to these face-to-face assessments, or are you still of the opinion that it will be almost everybody?

**Maria Miller:** I reiterate the point that the face-to-face assessment is only part of the way we would assess somebody's requirement for support, so for the individual you are talking about, who has very complex needs requiring some time to disentangle or to understand fully, obviously evidence can be put forward from specialists or an individual he is dealing with on a very regular basis.

**Q219 Teresa Pearce:** But would a face-to-face meeting add anything to that? Surely, that would be sufficient information.

**Maria Miller:** What the face-to-face assessment as part of the overall assessment will add is the ability for an individual to come forward and talk about their condition to make sure that they do not have to face a self-assessment questionnaire by themselves.

**Q220 Chair:** With all due respect, I think the point that Teresa Pearce is trying to get at is that there must be some conditions where any doctor's letter will say, "Because of this condition, the person is profoundly disabled." Therefore, why on earth do you need a face-to-face interview? Perhaps Dr Bolton can tell us the results of the pilot when the deafblind could not go through the assessment because translators could not be found for them. If you need a translator in order to interpret the assessment, surely that is the best illustration you need of the extra expenses associated with their disability.

**Maria Miller:** Just before Dr Bolton answers that, I was about to say that there will be individuals where there is sufficient evidence and there will not be a requirement for a face-to-face assessment. It would not be a good use of either that individual's time or taxpayers' money.

**Dr Bolton:** In the testing we worked with Sense, who represent people who are deafblind. They provided us with 41 volunteers, so we had a huge amount of information that was incredibly useful. They also did a report for us afterwards, which contained a number of very useful lessons that we are feeding into the development and delivery of all of this. That has been incredibly useful.

**Q221 Chair:** We have got the report and I was on the radio programme with one of the deafblind people. But what was your conclusion with the deafblind if

you could not find translators for them even to do the assessment?

**Dr Bolton:** Indeed. I think it highlighted a series of very practical issues. We set it up during a short period and it ran over a relatively short period of time. I think at times we did fall short, and we recognise that.

**Q222 Chair:** But, surely, if somebody who is profoundly deaf has to come to an assessment with a translator, that is evidence of an extra cost, and PIP is about meeting extra cost as a result of disability. Here is an example of people who clearly have extra costs as a result of their disability because even to get through the assessment they must have help from somebody else.

**Maria Miller:** But we want to make sure that the appropriate support is in place, and that individual may not just have communication needs.

**Q223 Chair:** Hold on, Minister. You are not putting the appropriate support in place; that is something for the local authority, or whatever. All you are deciding are the proxies that will give this individual extra money for them then to decide how they will purchase their support.

**Maria Miller:** But the proxies are both in daily living and also mobility. To take a step back, the reason we think it is important to look at people on a case-by-case basis is that we are trying to adhere to a more social model approach to assessment rather than simply pigeon-holing somebody based on their condition. If we are going to take that through to its logical conclusion, which I think we should, each individual needs to be looked at on a case-by-case basis. Clearly, there will be some individuals for whom face-to-face assessment is wholly inappropriate. If I go back to those who have terminal illness, or some who have particular conditions that can be corroborated through medical evidence, nobody will be advocating unnecessary meetings, but if we are to take a more social model approach here, it is important we look at people on a case-by-case basis.

**Q224 Sheila Gilmore:** I am finding it hard to reconcile that with your earlier statement that one of the problems with DLA was inconsistency, in that people with similar conditions could receive different outcomes. Surely, what you have just said will again produce exactly that, which may indeed be a good thing because people's needs do not necessarily derive directly from their condition but from all the circumstances. The social model is precisely about seeing that people's circumstances are different, so you will get different outcomes. Therefore, you will still have a lot of different outcomes.

**Maria Miller:** Not for individuals who face similar barriers. That is where we want to get consistency.

**Q225 Sheila Gilmore:** Not where people have similar medical conditions but face similar barriers, because earlier you talked about people with similar medical conditions or disabilities receiving different outcomes.

**Dr Bolton:** I think that is the key. Because what we are looking at within the assessment are different activities. Any given medical condition or impairment will affect individuals in a different way. We do not know what that is. One of the advantages of face-to-face assessment is that you can see exactly; the individual can tell you in their own words and demonstrate to you, if necessary, how conditions affect them. One thing I would like to make clear about testing is that this was not a pilot of how we would expect to run things once PIP went out; it was about information gathering to help inform the development of the assessment. There may have been people involved in the testing who had very clear problems and who you may never want to see because their level of disability is very clear and it would be unnecessary to do that. The testing was to go out and try to gather broad information on a whole range of impairments to help inform the development of the assessment.

**Stephen Lloyd:** I think testing is good and the social model is spot on. My advice is that, even when you are doing something right, like the social model, have some flexibility, because to test the deafblind is demented. Have some sort of flexibility, even if it is having five reports from their GPs, medicals or what have you. The social model is absolutely spot on and I heartily approve of what you are doing, but, if you do not have any or inadequate flexibility, there will be some people with very specific and profound disabilities where it is almost criminally insane to do a face-to-face assessment. That is my advice.

**Q226 Teresa Pearce:** I have a final question about delivery of the assessment and whether or not you believe there are sufficient companies with the experience to deliver the assessment so there would be proper competition. One thing we discovered with Atos and the work capability assessment was that the contract was drawn up on the basis they would be paid per assessment and there was no penalty for incorrect assessments; it was just for processing people. There is nothing about the standard. As for this particular group of people, what happened in the Atos contract was that, if people did not turn up, nobody followed up to find out why that was. For these people it will be very important to follow up why they do not turn up, because it could be something extremely serious. What is the number of companies out there that you think would be able to deliver this? It is very complicated.

**Maria Miller:** Perhaps I may deal with the first part of the question and then leave the officials to deal with the more commercial part of it. We are already working with disabled people's organisations on delivery. We know about the work capability experience and Professor Harrington's comments about making sure the claim and assessment process is a good and positive experience for claimants. We know that from WCA experience, but also, from the basic principle of making things work properly, we need to make sure we listen to and co-produce the claims and assessment process with disabled people. That is already an ongoing piece of work. In terms of the organisations who may deliver this, the Committee

will be aware that we have already started the commercial element of the procurement process so there is not a lot of detail on which I can comment. Perhaps Simon wants to assist.

**Simon Dawson:** As the Minister said, the formal competition for the independent assessment provider is ongoing, so it is probably not appropriate to be discussing details of potential bidders or to speculate on the outcome, but I can reassure the Committee that there has been a considerable level of interest at this stage from a range of suppliers. We are fairly confident that there will be a sufficiently robust competition for us to be able to complete this piece of work. We have fairly recently commissioned some research into the health professional resource in the marketplace. That has now concluded, and we will use the outcomes of that research to inform both the commercial approach and the way in which we include that in the overall design of the Personal Independence Payment.

**Q227 Chair:** Will one company get the contract, or will there be competition within the contract as there is in the Work Programme, or will it all land on Atos 2 or whatever?

**Maria Miller:** At the moment, we are looking at the details. We will make sure that our commercial strategy is informed by all the feedback we get from the market.

**Simon Dawson:** It is something we are considering in terms of the commercial approach.

**Q228 Chair:** On a practical note, who will go through the migration first? Will you start with a soft approach? Will it be new claimants first, or will you bring in a particular age group? What time scale is involved in all this? Who will you hit first, and how will you decide the order in which people will be called in for interview for the new assessment?

**Maria Miller:** The details will be set out in the new year. I think we will undertake consultation on this, but our starting point is that we would look very much at new claimants and then build up from there, but any order of migration is something we would want to look at in detail through consultation.

**Q229 Chair:** I advise you to make sure that is very clear. I speak as someone who was elected when the Benefit Integrity Project suddenly exploded on the scene in 1997 and was aware of the fear and alarm it caused to exactly the same group who would be getting reassessed under the new PIP criteria.

**Maria Miller:** I understand there is a great deal we can learn from the previous administration about changes to DLA. There were considerable problems to do with that.

**Q230 Chair:** It was something the previous Conservative Government left to explode in the face of the new government. When you are sending out these kinds of letters to people who have profound disabilities, which is the cohort of the group who will be affected by this, it can have a destabilising effect on them and their lives.

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**Maria Miller:** We would always want to make sure that migration to the new benefit is handled in a fair and transparent manner to avoid some of the past problems to which you allude.

**Q231 Harriett Baldwin:** I suppose that in terms of communications one of the things we have heard from a range of different sources is how widely it is thought DLA is just an out-of-work benefit. To what extent is one of the goals of rebranding DLA as Personal Independence Payment to try to help reduce that misperception?

**Maria Miller:** That is perhaps one issue, but there are many other reasons why we made a conscious decision to name the new benefit the Personal Independence Payment. For me, one of the most important reasons is that people felt the word “disability”, although broadly understood and accepted, was not always seen as related to people who had mental health conditions or other conditions; it was felt to be more directly linked to people with physical disability. In trying to press forward with a modernised view and benefit, it was absolutely entirely right to go for a name that talked about the overwhelming objective here, which is independence, and not put anybody off from claiming it because they might not label themselves as a disabled individual.

**Q232 Harriett Baldwin:** Are there any specific steps that you would take differently to ensure that the new benefit is well understood, in particular the point about it being available whether or not you are in work?

**Maria Miller:** Absolutely. We will be working with disabled people and their organisations to make sure there is a clear understanding of the role of the benefit and, very importantly, to try to continue to work with the media, who often conflate Incapacity Benefit, Employment and Support Allowance and Disability Living Allowance into one big pot and can create some confusion there as well. I think that across the board it is a matter of making sure people understand the system and, hopefully, as a result of the introduction of the Universal Credit, some of those complexities that perhaps caused the confusion will also disappear, which I think will be helpful.

**Q233 Harriett Baldwin:** Will you be using other arms of Government—I am thinking of employment service providers perhaps on the Work Programme, and NHS staff—to help communicate the fact that the benefit can be claimed irrespective of whether you are in or out of work?

**Maria Miller:** We would accept any help and support on this, but particularly what is already offered through Jobcentre Plus, our specialist disability employment advisers and also our general employment advisers, who have training and knowledge of when individuals are able to claim benefits. But, first and foremost, it is a matter of making sure we have an understanding among the general public that this is something available to people with a wide range of disabilities, and building on that to say that it is also an in-work and out-of-work benefit.

**Q234 Harriett Baldwin:** We have heard that Baroness Campbell has proposed changing the name to “disability living cost allowance”, or perhaps “disability living cost payment”, which is felt to reflect its purpose quite effectively. Has the Department test-marketed the phrase “Personal Independence Payment”, or any of these other possibilities?

**Maria Miller:** I think that the debate in the Lords on the name was very important because, as some of the individuals who have given evidence to the Committee have quite rightly said, what is most important is what it does rather than what it is called, but what we call things also has a resonance with people and it communicates what something is there for.

We undertook a series of focus groups to look at this in some detail well before we put the name Personal Independence Payment out into the general domain. Looking at some of the other ideas you have just talked about, we got some important feedback. Individuals felt that the word “disability”, although it was understood, related to physical disability, and that perhaps the idea of an allowance was a little paternalistic. In trying to project a very modern benefit for the 21st Century and supporting people to live independently, I was at great pains to make sure we did not have something that echoed the past and was in any way seen to be paternalistic or old fashioned in its views or demeanour.

I realise this is a somewhat subjective area, and I am sure there are companies up and down the country charging great amounts of money to decide on names for products. I can assure the Committee that the Government did not spend great amounts of money on deciding on the name Personal Independence Payment, but it did draw on some important insights into some of the real issues that many disabled people feel they face. They do not necessarily call themselves disabled and yet they would be eligible for this benefit. We have to take these things into account.

**Q235 Harriett Baldwin:** One thing that has struck me most when I have met disabled groups in my constituency is that, because of the name change, there is a perception out there among some of the most vulnerable people that DLA is going, whereas it is being replaced with a different benefit. What are your thoughts on that communication as well?

**Maria Miller:** You are right in the comments you make. What is important here is that we are continuing not just with the Personal Independence Payment but also the £40 billion a year support for disabled people and a real commitment across Government to support people. Perhaps some of the coverage around this change has been unhelpful in suggesting that support is evaporating or disappearing in some way. That is absolutely not the case. I would hope that, as we move forward, organisations we are working with will be able to reassure the people they represent that this is not the case. It really is not helpful if people live in fear of something happening that may not happen, which includes some of the speculation about the future number of people who will be supported by the benefit. I think that until

things are finalised it is important that we talk in facts as opposed to supposition.

Perhaps I may give the Committee a thought on that. We are very much committed to working by a method of co-production with disabled people on the development of this benefit. It is the right thing to do, but it brings with it some problems. The problem it brings is that you often have to talk to people about things before you know all the answers, so we bring out a draft assessment framework before we know exactly how this is going to work because we want to involve people in that conversation and dialogue, listening to their thoughts. In the case of the assessment, my colleagues, under the guidance of Dr Bolton, have done a fantastic job in listening and acting on those concerns. But sometimes bringing forward that method of co-production raises more questions than answers. It is really important that people resist the temptation to fill in the gaps with conjecture, because it is not helpful.

**Q236 Harriett Baldwin:** Another angle on the communication side is the decision taken about 20 years ago to move to a form to assess DLA. The fact that the majority of claimants for DLA have been assessed on the basis of a form is not what we would think is a news story, but the *Daily Mail* ran a story about a “staggering” 94% of new claimants of DLA receiving their payments after only filling in paperwork, as if this was a shocking piece of news, yet that is the process at the moment. Again, communications around that, as we said in our report on Incapacity Benefit migration, are so sensitive, not only because it is a very sensitive area but because a lot of those who make these claims are some of the most vulnerable people in our communities. I just wonder whether you have any thoughts on how DWP can make sure the message gets out in a clear way that cannot be exaggerated by the *Daily Mail*. It is probably wishful thinking by politicians.

**Maria Miller:** I think the point you raise is a very important one. Through a desire to be transparent in the way we operate and by wanting to make sure people understand the facts and figures, we publish a great deal of information sometimes on an *ad hoc* and sometimes on a very structured basis; indeed, many of the national statistics are available through a tabulation tool on the DWP website that allows people to have access to the data. Obviously, they need to use that information responsibly. We have an excellent press department that provides context for people who contact us, but it requires people to contact us to be able to give them the context in which those data might be best viewed. It is very difficult for us to control the way the media choose to interpret information. Obviously, we would always do everything we can to ensure that information is put out there in the right context. But perhaps a much deeper point is that the press perhaps are reflecting a mood that we need to make sure our benefits system, whether it is DLA or elsewhere, has the integrity it needs and confidence of people to support the people who need that help. Perhaps we also need to take that into account. That is another reason why the development and launch of PIP, which I think has

much stronger integrity, will be such an important thing for disabled people.

**Q237 Stephen Lloyd:** Minister, I am very glad to hear that. It is an issue about which I have spoken a great deal. On the back of what you have said, may I have a commitment that once this change has happened the DWP and you, if you are still the Minister for Disabled People, will go out and proactively sell how this is working and how people in receipt of it have disabilities and they are perfectly entitled to it? It has been a bit of a firestorm over the last year. I don't accuse you, because I think you have handled it very sensitively, which I respect. I don't think all Ministers have, but you have. When those changes do come through I would really like to see the DWP and the Ministers be very positive, on the front foot, about how important and justifiable it is for disabled people to receive PIP.

**Maria Miller:** I would underline that we take the issue of the language we use very seriously—all Ministers do—and we are clear it is the system that has trapped people into a spiral of welfare dependency, and it is the system that needs to change. Mr Lloyd is absolutely right that we have to make sure people not only understand what PIP is designed to do but that we are promoting it as a method of support, because it is important support. We want to see more disabled people being able fully to participate in our communities, whether that is in work or in other ways, and it is through the support of things like DLA/PIP that they can achieve that. We also have other strategies in place. Access to Work is another. I would reassure him that the strategy we are currently co-producing with disabled people will pick up many of these points and will definitely also serve to underline the points he is making.

**Q238 Harriett Baldwin:** Will part of the goal of achieving a new UK disability strategy be to show how the Personal Independence Payment is helping many disabled people to make a contribution, including as taxpayers?

**Maria Miller:** To take a step back from that, it is all about making sure people understand the importance of disabled people's role in our society and breaking down some of the very real problems people face in contributing to our society today and reaching their potential. Of course, one way of disabled people being able to reach their potential in society today is to make sure they have the right support in place and access to it.

**Q239 Karen Bradley:** I apologise for my late arrival—the Prime Minister's statement went on for longer than anyone anticipated. On the subject of the draft assessment criteria, we have had evidence of concern that the way they are currently designed means it assesses an individual's impairments rather than the additional costs of disability. One example given is that the moving around descriptor awards 12 points to someone who cannot move themselves up to 50 metres without using a wheelchair propelled by themselves, but you get 15 points if you need another person to push you, or a motorised device. The

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evidence we have been given is that those two people may have exactly the same additional costs of disability, even though their impairments may be slightly different. Perhaps you would comment on how the draft criteria were established, with particular reference to the additional costs and the aids and appliances involved.

**Maria Miller:** The criteria are all about trying to identify relevant proxies for the sorts of additional costs that disabled people face. When it comes to these more technical questions, I look to my right.

**Dr Bolton:** The assessment is not a fully social model, but, in exactly the same way, it is not a medical model at all. We do not really look at impairment as I would define it medically. The example you gave was very helpful, in that it shows some of the discussions we are now having about the weightings. We have only recently published the weightings, and they are, if you like, a first indicative look that we came to after developing that with our assessment development group, which involved a series of independent people. We are now having a series of meetings with different disabled people and organisations to look at some of those data and ask, “Will the costs be any different? Is this a good measure? Have we got these weightings broadly right?” We used the assessment criteria and weightings as we have them against the testing that we performed over the summer. What we have done with this version—there are two—is something that is reliable and valid. We did the same validity and reliability test of the first version, which we published back in May. I have to say they were neither reliable nor particularly valid, and it is all the work we have been able to do through consultation, co-production and working with disabled people that has got us the much better version we have now. We can finish working on some of the fine detail about the weightings before we go on to look at the impact of this and publish further information on that.

**Maria Miller:** We are finalising the weightings and new assessment right now, and we will come forward with thresholds and go to another round of consultation in January.

**Q240 Karen Bradley:** That answers one of my questions about when the criteria would be finalised and whether there is further scope for consultation. That is very helpful. The only other point—you have answered quite a lot of the points raised—is the specific reference to fluctuating conditions, and whether there is likely to be any change in the criteria. We have heard evidence that it would be “a nightmare for assessors and claimants” to try to assess the impact of the fluctuating condition being experienced more than half the time over a 12-month period. Is this the sort of thing on which we may see some movement?

**Dr Bolton:** Indeed. In the second version of the criteria we recently published we again put forward this proposal of a slightly different approach to fluctuating conditions. Instead of talking about the majority of the time, we talk about the majority of days, which I think is something people can probably understand much better and, hopefully, is much simpler in terms of its application. We are very grateful to Lord McKenzie in the Lords Committee

who said that the new draft criteria contain welcome recognition of the need to ensure that people with fluctuating conditions are not disadvantaged. It is an area that we have been looking at very closely. Again, going back to our testing, we made sure we had lots of individuals in there with fluctuating conditions, and we have been able to look at that very closely in the work we have been doing. As the Minister has already highlighted, we shall be starting formal consultation next year, and it is an issue we can look at again in our latest proposals.

**Maria Miller:** When we consider ability we will also consider whether activities can be completed safely, reliably and repeatedly in a timely manner. If they cannot, because of pain, fatigue or risk of an accident, it will be considered that an individual cannot undertake that activity. We are looking at this in great detail. We know it has been an area of real concern. We have been listening to people’s concerns and trying to adapt the way we approach this to give them confidence that the assessment will support them in the way we know it needs to. It is in our interests that we get this right.

**Q241 Karen Bradley:** Will the criteria be flexible enough to take account of how long a task takes, not just whether you are able to do it or not? We heard evidence in the Committee’s trip to Neath about a gentleman with Parkinson’s taking a bath. He could take a bath but it might take a long time, and therefore he might need extra support to enable him to do that.

**Maria Miller:** To be clear, it is that activities can be completed safely, reliably, repeatedly and in a timely manner.

**Q242 Chair:** If there were to be a truly social model on which you operated, you would take into the account the need for adaptations, but they do not feature anywhere in your criteria. Who are you assuming will pay for the adaptations if they are not part of the criteria that will give people money through PIP?

**Maria Miller:** We are going to deal with aids and adaptations in exactly the same way as they are dealt with under Disability Living Allowance, so there is no change in the way we will deal with that.

**Q243 Chair:** Remember, you are trying to improve it, and very often it is other things. At the moment, the fact that somebody uses a wheelchair acts as the proxy; it is assumed that they will have extra expense in terms of adapting. You talk about using appliances but not about adapting. That goes back to the “wet room” argument we heard earlier. It operates in that respect, but under the new PIP the use of a wheelchair by itself does not get you the full number of points.

**Dr Bolton:** To be clear about our approach to aids and appliances, the approach we put out in the first draft of the criteria was slightly different from what was in DLA. We consulted on that extensively. In the second version we have changed our approach. The approach has gone back to that under DLA. One thing I would highlight is that within the criteria we do pick up where there are aids, appliances, adaptations and so on being used. The key thing in all these activities is

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to look at how the individual is able to do that in a normal environment, if you like. If anything has to change about that environment and it has to be adapted around them, or they need aids or appliances to help them do that, they will move down the descriptors and an appropriate weighting is given for that. Again, part of the work we are doing at the moment is to make sure we have those weightings quite right and having discussions on making sure the criteria reflect those correctly.

**Q244 Chair:** That is where a lot of the costs for those with physical disabilities arise for which they use DLA. Some of them borrow against the DLA in order to make adaptations to their home, work environment or whatever when they cannot access it through Access to Work or facilities grants. We know that those things are limited. That helps to save government money because people have control over what they put in their house, whereas through facility grants you get what you are given and often that is the expensive thing.

**Dr Bolton:** Absolutely. Those are the kinds of things we are trying to pick up with the assessment as we have developed it. I have been talking a lot today about the testing. The way in which we did the testing was to get in groups of independent experts to look at our cases completely separate from the criteria and at the information gathered and give an indication of what they felt was the level of need. It was against that that we then made our assessment and the weightings applied and compared the two. There was very good correlation. That is how we know that what we have here is working in a very reliable and valid way.

**Q245 Chair:** One of our witnesses said to us that in this whole process there are no winners, only losers. What is your response to that?

**Maria Miller:** I disagree. The approach I outlined when we started this session today clearly states that we want a benefit that better reflects the way we as a society want to support disabled people in the 21st Century rather than two decades ago. I would expect to see people who perhaps in the past have been somewhat short-changed by DLA get proper support in the future, and the groups of people I have outlined in my previous answers to questions have already given the Committee some examples of where we will see real support for people who perhaps in the past have not had the help they needed.

**Q246 Chair:** And if that costs more money?

**Maria Miller:** We are being very principled in this approach, but we are, as the Committee knows, clearly living in an environment when we are trying to deal with an enormous deficit, so for everybody's sake, including disabled people, we have to make sure we have a benefit that is sustainable into the future. We will be spending the same on PIP at the end of the Spending Review period in 2015 as we spent on Disability Living Allowance last year, and that is after eight years of growth amounting to 38%.<sup>7</sup> The Government remain committed to Disability Living Allowance, but I think the broader support in the form of the £40 billion we put in every year to support disabled people through services demonstrates we are very committed to making sure disabled people have the support they need to live independent lives where they face challenges in doing so.

**Chair:** On that, thank you very much for giving us your time this afternoon.

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<sup>7</sup> This refers to an increase in overall Disability Living Allowance spending in real terms from 2002–03 to 2010–11 (2011–12 prices).



# Written evidence

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## Written evidence jointly submitted by the Centre for Mental Health, Hafal, Mental Health Foundation, Mind, Rethink Mental Illness, the Royal College of Psychiatrists and the Scottish Association for Mental Health

### 1. Introduction

1.1 Our organisations deal directly with thousands of people with mental health problems and represent the interests of hundreds of thousands more. Many of these people currently benefit from the support that Disability Living Allowance (DLA) provides and many more could and should receive the benefit but currently do not.

1.2 We have very serious and wide ranging concerns about the proposed move from DLA to the Personal Independence Payment (PIP) including: the offered justifications for the reforms; the manner and content of the proposed assessment process; and the likely impact on people with mental health problems.

1.3 Below we have addressed some of the key questions laid out by the Committee. We would be happy to offer further clarification or detail on any of the points made below and have included details of our organisations and key contacts at the end of our submission.

### 2. The need for DLA reform, including: how well understood DLA is; why the DLA caseload and expenditure has increased; the effectiveness of the decision-making and review process for DLA

2.1 We accept that there is scope for improving and reforming DLA. Indeed, we have long-held concerns that the benefit does not adequately support people with mental health problems due to issues with the application process and general understanding about how DLA can help people with mental health problems.<sup>1</sup>

2.2 Although we support some of the principles for reform outlined in the DLA Reform consultation document, we believe these are incompatible with the parallel objective of a 20% saving in the DLA budget.<sup>2</sup> The integrity of an objective assessment is heavily compromised if decisions are felt to be influenced by a savings target and available budget. Rather than creating a transparent and consistent system, claimants will believe their case has been assessed against available budget, not based on the support they need for independent living.

2.3 Furthermore, we do not believe that the Government has presented any robust evidence to support the decision to aim for this saving as part of the reform process. The principle basis of their argument appears to be that “In just eight years, the numbers receiving DLA has increased by 30%”. This rise has apparently been described by the DWP as “inexplicable”.<sup>3</sup>

2.4 Yet others have offered detailed analyses suggesting that large parts of this rise are explained by changes in demography and the “maturing” of the benefit.<sup>4</sup> In a subsequent publication the Government recognised the impact of these trends, which calls into question why such explanations were not included in the original proposals and consultation.<sup>5</sup>

2.5 In addition, growing awareness of the benefit among different groups, including people with mental health problems, and the development of case-law relating to eligibility over time means that growth in caseload is clearly a complex matter and not simply a sign of “wider application than originally intended”. It is also worth noting that fraud rate for DLA is very low at just 0.5%.<sup>6</sup>

2.6 Although reliable estimates of uptake of DLA are not available, there is a clear consensus among many clinicians and welfare advisers that large numbers of people who would be eligible for the benefit are not claiming.

2.7 All of this suggests that reform is focused on cutting the cost and therefore the caseload of DLA is driven more by a desire to save money than by a concern for the effectiveness of the benefit.

2.8 Another reason cited by the DWP for reform is the need to reassess claimants. In support of this, the Department has focused on the number of people who have been on the benefit for long periods of time. However, the DWP has failed to offer a detailed analysis of whether this is actually due to a lack of reassessment or simply people with long-term or permanent conditions. We are not necessarily opposed to reassessment but, since the process can be so stressful for claimants, we believe that existing medical evidence should be used wherever possible. We have not seen any evidence to suggest that more frequent and rigorous checks of medical evidence could not be built into the existing DLA system.

<sup>1</sup> Currently only around 16% of DLA claims are primarily for mental health problems, compared to over 40% of claims for incapacity benefits (we would not expect exact parity, as the benefits are for different purposes, but the disparity does nonetheless seem to be indicative of poor take-up of DLA among people with mental health problems).

<sup>2</sup> HM Treasury (2010) *Budget 2010*.

<sup>3</sup> <http://www.dailymail.co.uk/news/article-1353111/Disability-benefits-Half-claimants-asked-prove-eligibility.html>

<sup>4</sup> <http://opinion.publicfinance.co.uk/2011/08/disability-stats-devil-in-the-dwp-detail/>  
<http://www.leftfootforward.org/2011/02/rise-in-disability-living-allowance-explained/>

<sup>5</sup> [http://statistics.dwp.gov.uk/asd/asd1/adhoc\\_analysis/2011/DLA\\_Growth\\_in\\_Caseload\\_FINAL.pdf](http://statistics.dwp.gov.uk/asd/asd1/adhoc_analysis/2011/DLA_Growth_in_Caseload_FINAL.pdf)

<sup>6</sup> <http://statistics.dwp.gov.uk/asd/asd2/fem/nsfr-final-120711.pdf>

*3. The implications of a reduction in expenditure, including: the implications of focusing on those with the greatest needs; the likely impact of having only two rates of PIP in the “daily living” component; the number of current DLA recipients who would not be eligible for PIP*

3.1 We are very concerned that large numbers of people currently claiming or eligible for DLA due to their mental health problems will not qualify for the new benefit. It is unavoidable that a 20% reduction in the future budget of the benefit will mean that a substantial number of people will lose out and that, if the reassessment is on the basis of “greatest need”, these people will come largely from the lower rate of mobility and the lower or middle rates of care. Of around half a million current claimants for whom mental health problems are the primary basis of their claim, over 70% are claiming lower rate mobility, lower or middle rate care, or a combination of the two.<sup>7</sup>

3.2 In general, feedback from people with mental health problems who receive the benefit has been that it provides vital support, that it helps maintain independence and social participation, and that it plays a preventative role in terms of helping people maintain their mental wellbeing. As such, we believe this savings target will create a false economy as people perceived to have low level support needs may have support removed, leading to higher health and social care costs in the long term. There is a danger that the preventative role DLA plays for people with mental health problems will also be overlooked. People rely on DLA to cover costs essential to accessing support and keeping connected to social networks which can be vital both to their recovery and managing their condition. In a Mind survey from 2004, over two thirds of people with experience of mental distress reported that isolation caused or contributed to their mental health problems.<sup>8</sup>

3.3 As such, we have serious concerns that, despite the rhetoric about focusing support on those with the “greatest need”, a significant number of people with mental health problems will lose DLA and this will have a serious impact on their health and wellbeing. Unless the Government can make a clear and robust case that these people no longer need the support that DLA provides, or that they will receive this support in another way, then we can only conclude that the reforms represent a backwards step in efforts to achieve equality and independence for disabled people.

3.4 We are aware that the Government has been critical of estimates made by charities and representative organisations about the number of people likely to lose out as a result of these reforms. We would be very interested to see evidence to show how this analysis is incorrect as we believe it is crucial that an attempt is made to quantify it, allowing a full Equality Impact Assessment to be carried out.

3.5 The focus on “greatest need” is somewhat at odds with the original intention of DLA of paying towards the additional costs of disability. Research by Scope and Demos suggests that “greatest need” is not a very good proxy of additional costs and that a much more multi-dimensional and complex assessment is needed to accurately gauge levels of disability-related costs.<sup>9</sup> Such an assessment could also allow government to look to address the causes of these additional costs, in line with the social model of disability.

3.6 Our submission for the original consultation on DLA reform included survey responses from almost 200 current claimants and covered issues such as what DLA is used for, what the impact of the introduction of a face-to-face assessment would be, and how people expected the reforms to affect them. This document is included as an appendix to our submission.<sup>10</sup>

*4. The extent to which overlaps in funding exist, particularly with local authority and NHS funding, and including for people in residential care or hospital*

4.1 We are very concerned that the group of people we believe are most likely to lose out from these reforms are also very unlikely to be eligible for additional support from elsewhere. We know that many councils are raising their eligibility thresholds for social care, and other discretionary support (such as Freedom Passes in London) is also becoming harder to access.

4.2 There is a serious danger that people with moderate needs will find it hard to access a whole range of support and services and that this will have a negative knock-on impact on their health. It seems extremely short-sighted, and incompatible with the NHS emphasis on prevention, to only begin to properly support people when their needs have become severe, at which point it is more complicated and expensive to facilitate someone’s recovery. This is particularly worrying since people with mental health problems are already more likely to experience debt and live in poverty.

4.3 The intent to focus on “greatest need” in the assessment rather than making a serious attempt to look at additional costs may reinforce this gap in provision as it means that the support people are already receiving, and hence whether these costs are being addressed, will not be taken into account.

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<sup>7</sup> DWP statistics tabulation tool—<http://statistics.dwp.gov.uk/asd/index.php?page=tabtool>—These figures refer to all current DLA claimants, not just those of working age.

<sup>8</sup> Mind—Not alone? Isolation and mental distress. London: Mind, 2004.

<sup>9</sup> [http://www.demos.co.uk/files/Counting\\_the\\_Cost\\_-\\_web.pdf?1292598960](http://www.demos.co.uk/files/Counting_the_Cost_-_web.pdf?1292598960)

<sup>10</sup> Information provided, not printed.

*5. Whether automatic entitlement should apply to people with some conditions or impairments and whether some people should receive awards for indefinite periods*

5.1 We understand the arguments for assessing people based on their individual impairments, barriers and costs, rather than simply on the basis of their condition or diagnosis. This is particularly pertinent for mental health problems as people can experience the same diagnosis in very different ways. Mental health problems can also fluctuate dramatically so it can be very hard to predict how someone's condition will be at a particular point in the future.

5.2 However, this drive to individualise the assessment, and not to pre-judge someone, needs to be balanced against the profound impact on people's health and wellbeing that frequent reassessment can have. We have seen this negative impact on people being frequently retested for Employment and Support Allowance (ESA) through the Work Capability Assessment (WCA).

5.3 It is therefore important that efforts are made, where possible, to use existing medical evidence and the opinion of relevant health and social care professionals to avoid the need for a face-to-face assessment. The full assessment process should also only be repeated if evidence from these professionals suggests that the claimant's health has become significantly better or worse.

*6. The implications of a six month qualifying period*

6.1 We are deeply concerned that the increased qualifying period for PIP will mean that many people with mental health problems will struggle to access the benefit or will not receive it at the point at which it could most effectively support them.

6.2 We believe a delay in accessing adequate support in the early stages could result in people with mental health problems quickly becoming increasingly unwell. This could have a knock on effect on a person's ability to stay in work, stay connected to the support and social networks that would help them manage their condition and ultimately jeopardise or delay recovery.

6.3 The fluctuating and unpredictable nature of mental health problems also makes this qualifying period problematic. It would be difficult to predict the frequency, duration or severity of a mental health condition over a long period of time.

*7. The extent to which PIP will act as a gateway to other benefits, including Carers Allowance and the Motability Scheme*

7.1 We are concerned that without a full understanding of the impact of PIP, we can not assess the impact on carers.

*8. The design of the PIP assessment, including: the assessment criteria and design; whether the assessment can objectively assess those with mental, intellectual and cognitive conditions and with fluctuating conditions; and the extent to which aids and appliances should be taken into account in the assessment*

8.1 We have serious concerns about the draft design of the PIP assessment. We do not believe that "greatest need" is an accurate proxy of additional costs due to disability. However, even accepting the premise that the benefit should be awarded on this basis, we believe there are key areas of "need" that are not covered by the assessment.

8.2 Furthermore, although the scoring for the descriptors has not been included in the draft criteria, the content of the descriptors themselves suggests a very high level of eligibility. It is suggested that the descriptors are looking at "need" in the context of "participation" and that they are focusing specifically on the "pre-requisites for participation". However, it is clear that what is in actual fact being assessed is whether people are capable of the bare essentials of existence, with meaningful "participation" falling well outside the scope of the assessment.

8.3 We do not believe the assessment will be adequate for assessing the impact of mental health problems as it seems likely that it will repeat the mistake of the WCA of relying heavily on self-reporting. This means that people who have difficulty communicating about their condition or lack insight into the extent of their condition may well not have the impact of their condition accurately recorded. The draft criteria have also failed to preserve the parity of mental and physical impairments that has developed through case law for DLA. For example the definition of "assistance" is limited to physical help whereas, under DLA, encouragement required due to mental health problems is seen as equivalent to physical assistance.

8.4 We are encouraged that the technical note for the draft criteria talks about aggregating a condition over a 12 month period rather than simply taking into account how someone appears on the day. However, by only assessing applicants on the basis of whether they meet a particular descriptor 50% of the time, the draft criteria will inevitably miss many people with significant "need", additional costs, and barriers to participation, as described below.

8.5 Many people with mental health problems can be severely disabled less than 50% of the time, eg when a person has an acute episode of psychosis and is admitted to hospital for a three month period, but may not

be eligible for support under the new benefit. In comparison, someone with a more moderate impairment that is present for more than 50% of the time may be eligible. This does not appear to accurately reflect greatest need or additional cost. DLA currently allows the use of an “at worst” criterion which accommodates this. The proposed system would cause problems for many people with psychoses who would currently easily be seen as eligible for DLA.

8.6 We therefore propose that in order to accurately and fairly assess the impact of a mental health condition, the applicant should be asked about frequency, severity and duration of the impairments stemming from their condition and that the assessment should have the capacity to take account of each of these measures. Otherwise, the assessment is at risk of repeating the mistakes of the WCA and failing to recognise the true nature and impact of fluctuating conditions. Appendix 3 is an extract from the submission from Mind, Mencap and the National Autistic Society to Professor Harrington on improving the WCA descriptors, which shows how all of these measures could be incorporated into a single descriptor.<sup>11</sup>

8.7 Appendix 3 is our joint submission to the DWP regarding the draft criteria for the PIP assessment which includes more detailed analysis and criticism. Appendix 4<sup>12</sup> is the alternative criteria proposed by the Disability Benefits Consortium which some of our organisations were involved in proposing and which we believe offers a more comprehensive set of areas to be considered as part of the type of assessment proposed by the DWP.

*9. The delivery of the PIP assessment, including: who should carry it out; the approach to tendering for the assessment contract; who should make the award decisions; whether there are lessons to be learned from the Harrington review of the Work Capability Assessment; and interaction with other eligibility assessments*

9.1 Although we believe it is flaws with the policy that have most undermined the WCA, Atos has played a part in eroding the trust of disabled and ill people in the integrity of the process. It would therefore be highly undesirable to have Atos delivering the PIP assessment, due to both the widespread reports of bad practice and the low esteem in which the company is held by many people.

9.2 Indeed, with any private sector organisation there may be a conflict between ensuring the wellbeing of customers and seeking to maximise profit and it is vital that, in designing and contracting the service, Government seeks to mitigate this potential conflict. Furthermore, since the Government has been so keen to emphasise that the new assessment will not be a “medical” it is unclear why it needs to be carried out by medical professionals. Despite some problems with the current application form and eligibility criteria, decision-makers for DLA have become fairly adept, with the assistance of developments in case law, at making reasonable and fair judgements about eligibility. The introduction of a new layer of assessment is likely to prove costly, time-consuming, and stressful for those required to attend.

9.3 However, if the contract is to be tendered as expected then it is vital that the mistakes of the WCA are learned from and it is as robust and accountable as possible. It should include a mechanism for penalising the provider where successful appeals clearly show a shortfall in quality, professionalism or attention to detail at the assessment stage. The contract should ensure that sufficient time is given to properly assess applicants and that no targets are set for completing assessments that may place a downwards pressure on the time assessors give to each applicant. There should also be a transparent and effective complaints procedure for applicants.

*10. The steps DWP needs to take to ensure that its reform proposals are clearly and effectively communicated to claimants and the general public*

10.1 We believe that the introduction of the new benefit will have negative consequences for many people with mental health problems who currently claim, or could claim, DLA. Nonetheless, we also recognise that too few people were aware that DLA was a relevant benefit for people with mental health problems and that a new benefit offers the opportunity to change this perception. As such, it is important that every effort is made to ensure that the new benefit is presented as being as much for people with mental health problems as for those with physical disabilities.

10.2 Ideally, communication to the general public should emphasise the additional costs that disabled people face and how these costs can restrict independence and participation that non-disabled people take for granted. The benefit should be presented as vital support for disabled people to maintain their independence, dignity and health. It should also explained that the benefit is non-means tested, not dependent on employment status and that rates of fraudulent claims are very low for this type of benefit. We are concerned that the Government has not sought to publicly correct the significant amount of media coverage of DLA in recent months which has portrayed the benefit as a “handout” for people with minor ailments such as allergies; has suggested that very little evidence is needed to claim the benefit; and has falsely suggested that being on the benefit means you don’t have to work.<sup>13</sup> Many of these stories have included quotes from the Government.

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<sup>11</sup> Information provided, not printed.

<sup>12</sup> Information provided, not printed.

<sup>13</sup> <http://www.dailymail.co.uk/news/article-1321025/Disability-checks-force-400-000-work.html>  
<http://www.dailymail.co.uk/news/article-1370583/The-disability-benefit-thats-handed-alcoholics.html>  
<http://www.thesun.co.uk/sol/homepage/news/3383419/150m-payouts-for-an-allergy.html>

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## WHO WE ARE

### *Centre for Mental Health*

Centre for Mental Health is an independent, national charity that aims to help to create a society in which people with mental health problems enjoy equal chances in life to those without. We aim to find practical and effective ways of overcoming barriers to a fulfilling life so that people with mental health problems can make their own lives better with good quality support from the services they need to achieve their aspirations. Through focused research, development and analysis, we identify the barriers to equality for people with mental health problems, we explore ways to overcome those and we advocate for change across the UK.

### *Hafal*

Hafal is run by its 1,000 members—people with a serious mental illness and their families and carers. Every day our 160 staff and 150 volunteers provide help to over 1,000 people affected by serious mental illness across all the 22 counties of Wales. The charity is founded on the belief that people who have direct experience of mental illness know best how services can be delivered. In practice this means that at every project our clients meet to make decisions about how the service will move forward and the charity itself is led by a board of elected Trustees, most of whom either have serious mental illness themselves or are carers of a person with a mental illness. “Hafal” means equal. Our mission is to empower people with serious mental illness and their families to enjoy equal access to health and social care, housing, income, education, and employment, and to achieve a better quality of life, fulfil their ambitions for recovery, and fight discrimination.

### *Mental Health Foundation*

The Mental Health Foundation is the UK’s leading mental health research, policy and service improvement charity. We are committed to reducing the suffering caused by mental ill health and to help us all lead mentally healthier lives. We help people to survive, recover from and prevent mental health problems. We do this by carrying out research, developing practical solutions for better mental health services, campaigning to reduce stigma and discrimination and promoting better mental health for us all.

### *Mind*

Mind is the leading mental health charity in England and Wales. We work to create a better life for everyone with experience of mental distress by:

- Campaigning for people’s rights;
- Challenging poor practice in mental health; and
- Informing and supporting thousands of people on a daily basis.

A fundamental part of Mind’s work is provided through our network of over 180 local Mind associations who last year worked with over 220,000 people running around 1,600 services locally. Services on offer include supported housing, crisis help lines, drop-in centres, counselling, befriending, advocacy, and employment and training schemes. Over 30,000 people are supported by our national telephone help lines. Welfare reform is a key issue for many of the people Mind has contact with.

### *Rethink Mental Illness*

Rethink Mental Illness, the leading national mental health membership charity, works to help everyone affected by severe mental illness recover a better quality of life. We help over 52,000 people each year through our services and support groups and by providing information on mental health problems. Our website receives over 600,000 visitors every year. Rethink’s Advice and Information Service helps almost 8,000 people each year and advises people daily with benefit claims.

### *Royal College of Psychiatrists*

The Royal College of Psychiatrists is the leading medical authority on mental health in the United Kingdom and is the professional and educational organisation for doctors specialising in psychiatry.

### *The Scottish Association for Mental Health (SAMH)*

SAMH is a Scottish mental health charity which provides an independent voice on all matters of relevance to people with mental health and related problems and delivers direct support to around 3,000 people through over 80 services across Scotland. SAMH provides direct line-management to *respectme* (Scotland’s anti-bullying service) and “see me” (Scotland’s anti-stigma campaign).

## Written evidence submitted by Citizens Advice

### *Introduction*

1. Citizens Advice welcomes the opportunity to submit evidence to this inquiry. In 2010–11 Citizens Advice Bureaux saw 2.1 million clients and helped with 7.1 million issues. Benefits/tax credits and debt are the two biggest areas of advice, and account for almost two thirds of issues advised on. Bureaux handled over two million benefits and tax credit issues.

2. Groups at risk of poverty are over-represented among Citizens Advice Bureaux clients:

- 29% are disabled or have a long-term health issue.
- 15% of our clients are lone parents.
- 15% are from BAME groups.

3. Between July 2010 and June 2011, Citizens Advice Bureaux responded to 236,000 queries about the care component of Disability Living Allowance and 206,000 queries about the mobility component.

4. In order to inform Citizens Advice's contribution to the work on DLA reform, we consulted widely within our organisation, running two workshops for welfare rights workers and other advisers with a special interest in disability living allowance (DLA). Some of the advisers were also service users, and were members of other interested groups such as the Disabled Workers Group. These advisers have helped many thousands of clients, both directly—in helping to complete complex DLA forms and representing or preparing submissions for clients on appeal—and also indirectly—in supervising other advisers who help clients with the forms. Helping clients to complete DLA forms can regularly take between two and four hours and involves a very detailed exploration of the impact of the client's condition or impairment on their daily life, and the way their needs fit into current case law. We are very grateful to everyone who took part in this internal consultation, all of whom contributed a huge combined knowledge and understanding of the disability benefits system.

5. We believe the single most important issue to raise with the Committee is that the group of people who are likely to lose out from these reforms is the same group who are losing from many other reforms—ie those with significant but not the most severe level of condition or impairment. They do not necessarily have the lowest level of extra costs and as a result of these and other changes, we fear many will effectively become much more disabled by being less empowered, and ultimately more socially excluded.

### *The need for DLA reform*

6. The aim of DLA is to contribute to the extra living costs faced by people with a disability. It is recognised that estimating those costs directly for each person is difficult, so the amount of personal care someone needs is used as a proxy. We agree with the Government that this has led to a number of problems. It causes significant complexity and generates case law around the definition of “care in association with bodily functions”. More fundamentally, in many circumstances care needs are simply not a good proxy for extra costs. In the recent Demos/Scope report *Counting the Cost*,<sup>14</sup> a survey of 845 people with disabilities found that care needs were only a good proxy in a very limited number of areas of extra spending. We do therefore think that useful changes could be made to disability benefits. However, having looked at the proposed regulations, we have very strong reservations about the current reform process, which we do not believe will provide a good proxy for extra costs. We are contributing to a working group coordinated by Scope which is developing a possible alternative assessment.

### *Why the DLA caseload and expenditure has increased*

7. We believe there are a number of reasons for the increase in the cost of DLA:

- Take-up of DLA has always been poor: numbers are therefore bound to increase as more people discover they are eligible.
- Many conditions or impairments are very long term. Over time, there are more people who apply for the benefit before 65, and continue to receive it over 65.
- Disability years increase as life expectancy increases.

8. There is an assumption that because receipt is higher in areas of high unemployment, that claims must be linked with people's unemployment status, rather than a genuinely higher level of disability in these areas. In areas of high unemployment, life expectancy is also very low, which suggests that many more people are living through their “disability years” while under pension age. We are particularly concerned about the impact of reform on the group of people who claim DLA as their health deteriorates towards the end of life. We see clients in their fifties who have emphysema and heart disease, who struggle to walk more than 50 to 100 metres. They have a level of fitness equivalent to someone aged 80 to 85.

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<sup>14</sup> “Counting the cost” Wood and Grant published by Demos 2010.

*The effectiveness of the decision-making and review process for DLA*

9. Our evidence indicates that the decision making process for DLA—while not perfect—is significantly better than for ESA. In particular, the reconsideration process for DLA has for some time been much better than for ESA. When a DLA claimant appeals, the decision is reconsidered by a different decision maker. Our evidence demonstrates that when a good case is made with strong supporting evidence, the decision is often reconsidered favourably without going to a tribunal. Recently, however, there have been examples from bureaux where a WCA report arising from a 40 minute assessment (by a health care professional who doesn't know the claimant) is frequently accepted in preference to strong evidence from the claimant's own doctors.

10. We feel very strongly that there is no need to insert an extra stage in the appeal process, as suggested in the Welfare Reform Bill, which would require a client who wishes to go to tribunal to meet two legal time limits rather than one. This will mean that some vulnerable claimants with strong cases will not get the benefit to which they are entitled, simply because they miss the time limit.

*The implications of a reduction in expenditure*

11. We are very concerned that the reform process is being led by a decision to cut the costs of working age disability benefits by 20%. We believe this can only lead to greater social exclusion for some disabled people. We do not believe there is any evidence that the people receiving the benefit currently do not need the money. On the contrary, we think there is strong evidence that it currently does not meet the extra costs of disability, and that people who are disabled are much more likely to live in poverty than those who are not disabled.<sup>15</sup>

12. Our calculations indicate that even if all those who at present receive the lower rate of the care component do not receive the daily living component this will still only achieve about half the required savings. We are very concerned about the extent of the savings being proposed.

*The implications of focusing on those with the greatest needs; the likely impact of having only two rates of PIP in the "daily living" component*

13. As mentioned above, the group most likely to be affected by this reform will be those with significant but not the most severe level of condition or impairment. ESA regulations have been tightened so that this group are much more likely to be found fit for work and not receive the benefit. The extra support through Universal Credit for people who are disabled will go to many fewer people than the current disability element of WTC, since it will only be awarded to those who are found not fit for work (as opposed to people with reduced capacity for work). The proposal to change PIP such that the lower level of DLA is effectively removed, will also reduce the help provided to the same group of people.

14. Taken together, we believe these changes will not only mean a very serious reduction in income for this group, it will also have wider implications. Many local authorities and other organisations use benefits as a proxy for other support and help, such as travel passes, leisure passes *etc*—like the following concession offered by Camden:

*The disability card carries many of the benefits of the other wellness cards, but is only offered to those who are eligible for Disability Living Allowance (DLA). The card allows you and a carer free entry to the fitness centre, swimming pools and group exercise classes.*

15. *We believe that taken together these policies can only lead to greater social exclusion for some disabled people. It will further disempower some people with disabilities, as they will be less able to take part in society.*

*Automatic entitlement*

16. There are advantages and disadvantages to automatic entitlement. For some conditions or impairments where there is a very high chance of entitlement, automatic entitlement could save time and money for DWP, as well as relieving stress for clients. It is very unlikely that someone who is registered blind, for example, will have no extra costs associated with their impairment. However the disadvantage is that entitlement would be based solely on the medical model. The medical model doesn't identify the very different barriers to social inclusion faced by different individuals.

17. *We therefore recommend that automatic entitlement at a minimum level of benefit should be considered for some impairments or conditions, where it is clear that there are bound to be extra costs.* The actual level of benefit would then depend on an assessment of individual circumstances. An advantage of this model would be that take-up would be greater because people would be sure of receiving the basic level of benefit.

*The implications of a six month qualifying period*

18. We are very concerned about the proposal that DLA should have a six-month qualifying period rather than three months as for DLA at present. Citizens Advice Bureaux see many clients in serious financial difficulties, who often suffer an unexpected and very dramatic drop in income as a result of having to take a lengthy period of sick leave—because, for example, they have a diagnosis of cancer and need immediate

<sup>15</sup> See Citizens Advice report, *Double disadvantage*, June 2011.

treatment, or have a stroke or a serious accident. Surveys by Citizens Advice have consistently found that illness is a significant cause of debt in around a quarter of the clients we advise about debt problems. During 2009, a survey of clients with mortgage arrears seen at advice desks in the county courts (run by advisers from Citizens Advice Bureaux, Shelter and AdviceUK), found that 19% of the clients reported illness as a major factor in falling into mortgage arrears. The first three to six months are often the period when the extra costs are at their greatest, just as people are trying to adjust their outgoings to their reduced income.

19. *A Macmillan CAB adviser saw a client whose wife was receiving chemotherapy following a mastectomy for breast cancer. She felt very ill, and was in need of much care and help travelling to appointments. As her husband was the only person available to provide care, he had to take time off work. He only got paid for the days that he worked and did not have accrued entitlement to paid leave. The couple were struggling financially due to this drop in income and were running into debt during the three months they had to wait for extra financial help from DLA.*

20. If it is important to extend the likely length of time of the impairment to one year, we have suggested that a possible alternative is to keep the qualifying time at three months but extend the time someone is likely to have the same needs, from six to nine months. We believe this would still cause problems for some who have very high and intensive needs for about nine months (such as those going through cancer treatment or those recovering from a serious accident) but would be better on balance than the proposed six month qualifying time.

*The extent to which PIP will act as a gateway to other benefits, including Carers Allowance and the Motability Scheme*

21. We are concerned that the proposed reduction in financial help will lead to a loss of benefit for many people on middle rate care, leading to a loss of the right to Carer's Allowance for their partners. Similarly, if eligibility for the mobility component becomes tighter and fewer people have access to the motability scheme, more people will become housebound. There is already a gap between the level of mobility needed to use public transport and the criteria for receiving the mobility component.

22. *A bureau reported a man in his late fifties who had emphysema and struggled to walk due to pain in his legs and shortness of breath. He was unable to use public transport as he couldn't walk the distance to the bus stop, so could only get out when family and friends were able to provide transport. He had been refused the mobility component of DLA which would have enabled him to be more independent.*

*The design of the PIP assessment*

23. We welcome the Government's stated aim of increasing social inclusion. We do not believe the proposed regulations for PIP will achieve this aim. One of the conclusions from our workshops on DLA reform was that for many people with disabilities, the single biggest barrier to leading a full and active life is the inability to leave the house independently. The extra costs people face in getting out of the house vary enormously depending on their personal circumstances. We are concerned that the proposed assessment will not be any more effective than the present system at measuring extra costs if it does not take into account the disabling social and environmental factors of living with disability.

24. Reducing benefit for people with an impairment will effectively make many people more socially excluded, as they will be less able to take part in society.

*The delivery of the PIP assessment*

25. How people are assessed is absolutely crucial to the right outcomes in awarding benefits, and causes tremendous emotional and financial hardship if it is not done well. We believe that assessment falls into three stages:

- The collection of medical evidence from the claimant's doctor (or specialist).
- Evidence provided by the claimant.
- Verification of evidence.

26. Current assessments for DLA and ESA operate in different ways and we believe that there should be further research into the most effective methods for achieving appropriate outcomes.

27. We have observed evidence of significant problems with the accuracy of assessments for ESA, and are particularly concerned that a similar system will be used for PIP. *We believe that accuracy is the best criterion by which to measure the efficacy of the test.*

28. We recently conducted a survey to assess the accuracy of reports produced by health care professionals (HCPs) from the face to face assessments for ESA. We asked bureaux to identify claimants before they attended their assessments, in order to ensure that the sample was collected as objectively as possible. Claimants were asked to request a copy of their report and then compare the record in the report of what they said with what they thought they had said about the impact of their condition or impairment on their daily life. We also looked at the extent to which the points awarded were consistent with the evidence recorded in the report.



29. 37 reports were received.<sup>16</sup> We analysed them and grouped them into three levels of reported accuracy.

30. Reports were classified as having a serious level of reported inaccuracy if the client reported a very substantial level of inaccuracy *and* we judged this would be likely to have a significant impact on either the ESA award or a DLA award. 16 of the 37 cases were judged to be in this group.<sup>17</sup>

31. Reports were classified as having a medium level of reported inaccuracy if there was a significant level of inaccuracy and it could have affected a claim for ESA or DLA. Ten reports<sup>18</sup> were in this group.

32. 11<sup>19</sup> of the reports were classified as having a low level of reported inaccuracy.

33. *We believe that independent research is urgently needed to measure the accuracy of these assessments for ESA. If a similar process is to be used to assess claimants for PIP—or if the same assessments will be used—the imperative is even stronger.*

34. Evidence from the survey also reinforces the value of collecting additional evidence from the claimant's own doctors. *We reiterate our recommendation that DWP should routinely collect the evidence to avoid costs for claimants.*

*How DLA/PIP should apply to children and people over the state pension age*

35. We strongly recommend that PIP should not be extended to children without a full consultation and we will be keen to respond.

*Communication to claimants...*

36. We are working with Pensions, Disability and Carers Service (PDCS) to help inform their plans for delivery of PIP.

*...and the general public*

37. We have been very concerned about the tone of recent press coverage of benefits for disabled people. How the department presents PIP in the media will be crucial to public understanding. In particular we are concerned at how the reduction in numbers receiving disability benefits will be presented.

2 September 2011

### Written evidence submitted by the Disability Benefits Consortium (DBC)

1.1 The DBC is a national coalition of over 50 charities and other organisations committed to working towards a fair benefits system.<sup>20</sup> Using our combined knowledge, experience and direct contact with disabled individuals, people with long-term conditions and carers, we seek to ensure that government policy reflects and meets the needs of all disabled people.

#### SUMMARY

2.1 The Disability Benefits Consortium is very concerned over Government plans to abolish DLA for disabled people 16–64 years of age and replace it with the 20% less well resourced Personal Independence Payment (PIP).

2.2 Many DBC members have previously highlighted the need to reform DLA but we do not believe there is a strong case to reduce DLA expenditure by 20%; nor has the Government justified the level of the cut. We believe that “reform” is being used to cut expenditure and that the PIP assessment is undermined by being designed to reduce costs rather than reflect disabled people's support needs or ensure independence.

2.3 We believe DWP has failed to demonstrate that the Government has fully considered the potential impact of such a significant reduction in support for disabled people and their families, despite increasing amounts of evidence<sup>21</sup> of the risks involved. Failure to adequately assess the impact and mitigate the risks could see a judicial review of the DLA/PIP plans.<sup>22</sup>

<sup>16</sup> The sample size is necessarily fairly small, since this research was intensive and time consuming for bureau advisers—for a sample of this size for 95% confidence the sampling error will be around 16%.

<sup>17</sup> 43% of the sample—ie there is 95% confidence that the true level of reported inaccuracy is between 27% and 59%.

<sup>18</sup> 27% of the sample.

<sup>19</sup> 30% of the sample.

<sup>20</sup> See appendix one for a list of DBC members.

<sup>21</sup> Including, most recently, from the Papworth Trust: [www.papworth.org.uk/news-detail.php?aid=242](http://www.papworth.org.uk/news-detail.php?aid=242)

<sup>22</sup> The potential for a judicial review of DLA/PIP plans when the Welfare Reform Bill is enacted has been raised if DWP fails to address disabled people's concerns or analyse plans fully. See: [www.disabilityalliance.org/dlachallenge.htm](http://www.disabilityalliance.org/dlachallenge.htm)

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 DBC RESPONSE TO INDIVIDUAL ASPECTS OF THE I

*The need for DLA reform, including: how well understood DLA is; why the DLA caseload and expenditure has increased; the effectiveness of the decision-making and review process for DLA*

3.1 Many members of the DBC support reforming DLA. Many of the people we represent are aware of bureaucratic problems of the present system and the challenges for disabled people in identifying appropriate support.

3.2 However, the Government's rationale for reform has been disjointed. DWP have suggested a 30% growth in DLA claimants as one reason for abolishing working age DLA. But in August 2011 DWP revealed that growth of working age was closer to 16% once demographic changes and population growth were taken into account.<sup>23</sup>

3.3 The Government also claims DLA is widely misunderstood. DWP believe too many disabled people think DLA is an out of work benefit but the (exploratory) DWP research on this issue is inconclusive;<sup>24</sup> and there is also evidence on the number of disabled people not accessing DLA but entitled to support.<sup>25</sup>

3.4 If DLA was more widely misunderstood or there were greater decision-making/review process problems (as DWP have suggested) then we should expect the fraud rate of DLA to be far higher than the current 0.5% rate.<sup>26</sup>

3.5 DWP have also suggested that periodic review of claimants is required due to the length of time many disabled people have received DLA.<sup>27</sup> This misunderstands the effect of health conditions and/or impairments over time and seemingly expects all disabled people to "get better" or totally adapt to the disadvantage and higher costs of living experienced by disabled people.

3.6 Whilst some disabled people may adapt over time, the experience of the vast majority of disabled people differs and 91% of the disabled people receiving DLA have more than one impairment and over half (56%) have four or more impairments.<sup>28</sup>

*The implications of a reduction in expenditure, including: the implications of focusing on those with the greatest needs; the likely impact of having only two rates of PIP in the "daily living" component; the number of current DLA recipients who would not be eligible for PIP*

4.1 Research reveals that DLA has been used by disabled people since it was introduced in 1992 to support disabled people to pay: higher utility bills; medical and equipment costs not faced by non-disabled citizens; dietary costs; higher travel expenditure and other essentials for everyday life. DWP has not provided an assessment of the impact that a cut in DLA/PIP resources will have on disabled people's ability to meet basic daily costs.

4.2 Disabled people and their representative organisations are very worried about the impact of a 20% drop in DLA/PIP resources. The Papworth Trust recently surveyed 2,000 people and:

- 77% of respondents thought the cuts penalised disabled people;
- 59% would not have enough for basic household goods like food;
- 39% would not be able to purchase medication and therapies; and
- 34% may not be able to purchase essential equipment like wheelchairs.

4.3 These findings<sup>29</sup> help demonstrate the implications of reduced DLA/PIP use and support previous research evidence. The Disability Alliance survey on Government plans also found:<sup>30</sup>

- 62% of respondents feared cuts would increase exclusion and poverty;
- 35% reported finding it difficult or very difficult to get by already; and
- under 10% stated DLA covered all their disability-related costs but the benefit was most commonly used to contribute towards items like transport (89%), heating/laundry (68%) and aids/equipment (58%).

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<sup>23</sup> See: [http://statistics.dwp.gov.uk/asd/asd1/adhoc\\_analysis/2011/DLA\\_Growth\\_in\\_Caseload\\_FINAL.pdf](http://statistics.dwp.gov.uk/asd/asd1/adhoc_analysis/2011/DLA_Growth_in_Caseload_FINAL.pdf) The difference being explained by overall population growth, older disabled people retaining DLA entitlement past 65 years of age, and disabled children surviving into adulthood in greater numbers. Current reform is targeted up to the age of 65 and if over 65 growth in DLA use is exempted the figure for DLA growth is 23% from 2002–03 to 2010–11. The figure falls to 16% once the demographic change is accounted for (7%).

<sup>24</sup> See: <http://statistics.dwp.gov.uk/asd/asd5/rports2009–2010/rrep648.pdf>

<sup>25</sup> See: DWP research report 649, 2010 for example: <http://research.dwp.gov.uk/asd/asd5/rports2009–2010/rrep649.pdf>

<sup>26</sup> DWP estimate; see: <http://statistics.dwp.gov.uk/asd/asd2/fem/nsfr-final-120711.pdf>

<sup>27</sup> See the DWP release: <http://dwp.gov.uk/newsroom/press-releases/2011/apr-2011/dwp038–11.shtml> which suggests: "130,000 of those who were first awarded DLA in 1992 have never had their needs reviewed, or a change to their award, so we have had no way of knowing if their condition has changed and they still qualify for the benefit". DWP does have the power to review claims of course.

<sup>28</sup> Sainsbury, R *et al. Evaluation of Disability Living Allowance and Attendance Allowance*, 1995. Department of Social Security Research Report No. 41. See: <http://research.dwp.gov.uk/asd/asd5/rrep041.pdf>

<sup>29</sup> See: <http://www.papworth.org.uk/news-detail.php?aid=242> for the Papworth Trust report.

<sup>30</sup> The DA survey was used to inform the Disability Rights Partnership response to the DWP DLA consultation and the full response is available online at: <http://www.disabilityalliance.org/r68.doc>

4.4 The impact of cutting resources to current DLA recipients on disabled people's ability to meet essential daily costs is alarming.

4.5 We are also very worried that PIP comes with just two rates of "Daily Living" payments. The 652,000 working age low rate care DLA recipients are fearful that their support will be cut under PIP (which abolishes the level of support they receive). The total annual expenditure on low rate care payments amounts to £663 million which does not meet the 20% expenditure reduction target.<sup>31</sup> Disability Alliance estimates that over 750,000 disabled people could lose support as a result of a 20% expenditure cut and the abolition of low rate care support.<sup>32</sup>

4.6 Many people receiving low rate care DLA are unlikely to be eligible for alternative support (eg social care services) due to a pattern of ratcheting up eligibility thresholds to support only people with the highest levels of needs.<sup>33</sup> DLA has prevented some disabled people seeking or requiring council funded care services. The recent Dilnot Commission into adult social care funding reported that meeting lower level needs is essential to ensure prevention of higher or crisis level needs.<sup>34</sup> DLA's contribution to the prevention agenda may be lost under current DWP plans.

4.7 We fear that tightening support may also accrue costs for Government. Disabled people unable to access support may:

- be unable to manage a health condition (eg unable to afford prescriptions,<sup>35</sup> attend medical appointments or pay high utility bills resulting from maintaining a consistent home temperature), resulting in greater numbers of avoidable hospitalisation periods;<sup>36</sup>
- be unable to manage independently and seek cost-intensive council funded residential care;<sup>37</sup> and
- reduce or stop working. 27% of the respondents to one recent survey were both receiving DLA and in work but more than half (56%) said they would have to stop or reduce work if they lost access to support.<sup>38</sup>

4.8 DWP have not responded to requests to analyse these risks/costs.

4.9 Disabled people already experience significant hardship and disadvantage. A third of disabled people live in poverty in the UK and it is unlikely that restricting financial support will tackle this situation.

*The extent to which overlaps in funding exist, particularly with local authority and NHS funding, and including for people in residential care or hospital*

5.1 The Government has provided at least eight different reasons for targeting 78,000 disabled care home residents with cuts to DLA mobility support. One is "overlap" in funding. The DBC has responded to all the Government's attempted justifications.<sup>39</sup> We do not believe any of the reasons legitimise ending the current support framework for care home residents who face losing choice and control over resources designed to support independence and ability to participate.

5.2 We accept that there are different levels of support across the country and that some care homes and councils provide greater support than others. But ending eligibility for support is not a solution and puts disabled people at risk.

5.3 The Government has announced a review of this policy but it is less than clear what the terms of reference are or how evidence is being gathered. As a result of this lack of transparency, Lord Low of Dalston has established an independent review of the issue involving a range of stakeholders and resourced by Leonard Cheshire Disability and Mencap.

5.4 It is unclear as yet whether the Minister for Disabled People, Maria Miller MP, will be providing evidence to the Low Review. The DBC would welcome the Minister's involvement.

<sup>31</sup> 20% would be £1.3 billion based on 2010–11 working age DLA expenditure.

<sup>32</sup> See: <http://www.disabilityalliance.org/r68.doc>

<sup>33</sup> In a 2011 survey of Directors of Adult Social Services it was revealed that almost £1 billion is likely to be withdrawn from support for disabled people by England councils in 2011–12 to meet budget pressures at local level. This is often achieved by restricting access to care services through raising eligibility thresholds. 78% of councils only provide support to disabled people with "critical" or "substantial" needs. Disabled people with moderate and "low" assessed needs are being denied support previously available. For the full *ADASS Budget Survey* see: [http://www.adass.org.uk/index.php?option=com\\_content&view=article&id=732:adass-urges-government-to-include-findings-of-the-commission-on-the-funding-of-care-and-support-in-its-review-of-nhs-legislation&catid=146:press-releases-2011&Itemid=447](http://www.adass.org.uk/index.php?option=com_content&view=article&id=732:adass-urges-government-to-include-findings-of-the-commission-on-the-funding-of-care-and-support-in-its-review-of-nhs-legislation&catid=146:press-releases-2011&Itemid=447)

<sup>34</sup> *Fairer Care Funding*, Dilnot Commission, July 2011. Online at: [www.dilnotcommission.dh.gov.uk/our-report/](http://www.dilnotcommission.dh.gov.uk/our-report/)

<sup>35</sup> Disabled people in Scotland do not have to pay for prescriptions and may be able to access some free personal care from councils. The widening UK differentials in policy are enlarging the "postcode lottery" of support for disabled people.

<sup>36</sup> In the survey undertaken by Disability Alliance 16% of respondents suggested cuts to DLA would result in higher use or costs to the NHS. See: <http://www.disabilityalliance.org/r68.doc> and travel costs for disabled people include an average round-trip for cancer treatment of 60 miles for example, according to Clic Sargent: *A Long Way from Home* 2010 online at: <http://www.clicsargent.org.uk/Whatwedo/Impactoftravel>

<sup>37</sup> 14% of the DA survey respondents mentioned increased demand for council services being a potential result of cuts to DLA support, including care services and housing needs.

<sup>38</sup> Disabled people in work highlighted using DLA to fund travel. See: <http://www.disabilityalliance.org/r68.doc>

<sup>39</sup> See: *DLA mobility: sorting the facts from the fiction* online at: <http://www.disabilityalliance.org/dbcdla2.pdf>

5.5 The Government has also claimed disabled people will not lose out through the care home and eligibility changes. But it is unclear how and the DWP approach is incongruent with the aim of greater consistency and simplification across the welfare system. The Government approach could mean:

- disabled children (under 16) accessing DLA using the current system;
- disabled people 16–64 years of age accessing PIP;
- some disabled people over 65 retaining current DLA support;
- disabled people (new claimants) over 65 accessing Attendance Allowance using the current system;
- existing disabled care home residents currently using DLA mobility payments being afforded an unknown and transitional protection; and
- new disabled claimants in care homes possibly not being able to access PIP.

5.6 It is unclear how the Government plans to administer the exemption or transitional plans and how much this may cost to assess (or how appeals will be managed). It is also unclear if new care home residents will be eligible for a different source of support or if the Government intends to oblige care homes or councils to provide greater levels of support for new residents. The lack of transparency is avoidable and unhelpful but reveals the lack of consideration of the issue before the decision to axe support was announced last year.

5.7 The Government has been accused of breaching obligations to promote disabled people's equality of opportunity on welfare cuts and the lack of consistency, evidence and transparency in this area suggests a strong case under the Equality Act may be possible due to the lack of impact assessment before decisions were made to withdraw resources.

5.8 The DBC is also concerned that many inaccurate assumptions are made about what the NHS will fund for disabled people. Many disabled people use DLA to enable them to "top up" NHS funds and buy more appropriate equipment (eg a specific wheelchair which the NHS will not fund). DWP plans risk making people more reliant on limited NHS support.

5.9 Research and surveys have also demonstrated disabled people use DLA to manage health conditions in other ways (see paragraphs 4.2 and 4.7 above). DWP plans risk removing disabled people's ability to manage conditions. These issues have been raised but DWP has provided no answers concerning how these potential costs are being factored into Government plans. Disabled people fear that neither the Minister for Disabled People, DWP and the Office for Disability Issues, Department of Health nor the Department for Communities and Local Government is ensuring these cross-Government issues are adequately addressed.

*Whether automatic entitlement should apply to people with some conditions or impairments and whether some people should receive awards for indefinite periods*

6.1 The DBC does not believe ending automatic entitlements and requiring disabled people—and especially people with progressive conditions—to attend periodic reviews of needs is necessary or cost effective.

6.2 DWP is keen to reassess disabled people routinely, rather than make indefinite or long-term awards. DWP claims many people's needs reduce over time, but previous programmes of re-assessments of DLA claimants have identified greater needs and resulted in more higher payments than benefit reductions. Between 1999 and 2002 almost 69,000 people had DLA payments checked and:

- three quarters (74%) remained at the same level;
- 18% were increased due to needs having risen; and
- 8% (5,573) were decreased.<sup>40</sup>

6.3 The identification of rising needs in the previous programme may be a factor in DWP opting to abolish DLA rather than reform it through a programme of reassessments of disabled people with long-term awards.

*The implications of a six month qualifying period*

7.1 The DBC believes that increasing the qualifying period to six months will result in many disabled people and their families being pushed further into poverty and debt.

7.2 PIP is intended to provide support for disabled people to lead full, active and independent lives by helping with the additional costs experienced through impairments/health conditions. Making people wait longer will place further burdens on those adjusting to sudden onset conditions such as stroke, or people who experience the immediate debilitating effects of cancer treatments for example, as well as penalising those whose impairment or condition has gradually worsened over a period of time and have already had to deal with additional costs prior to passing the high threshold for PIP.

7.3 The Government's stated desire to align PIP with the definition of long-term disability in the Equality Act could be better achieved by retaining the three month qualifying period and extending the period of anticipated future need to nine months, rather than doubling the qualifying period. The Government's argument

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<sup>40</sup> See: *Son of BIP makes good* Dulip Allirajah in CPAG Welfare Rights Bulletin, 2002. Available online at: <http://www.cpag.org.uk/cro/wrb/wrb170/bip.htm>

that doubling the qualifying period for PIP will bring the benefit in to line with Attendance Allowance is flawed, since there is no prospective test for Attendance Allowance.

7.4 CLIC Sargent believe that, whilst DWP have stated the changes to qualifying period are not to generate savings, the proposed extension will discriminate against those with conditions such as cancer and is likely to remove eligibility altogether for those with shorter treatment periods. We do not believe this is the Government's intention and would welcome the retention of a three month qualifying period with an extension of anticipated future need to nine months.

*The extent to which PIP will act as a gateway to other benefits, including Carers Allowance and the Motability Scheme*

8.1 There is considerable anxiety amongst carers that the Government has not established how PIP will "passport" access to Carer's Allowance.

8.2 Currently, Carer's Allowance is accessed through middle and higher rates of DLA care payments. We believe both rates of the PIP daily living component should facilitate access to Carer's Allowance.

8.3 The Government has not yet estimated how many carers will be affected by the DLA/PIP changes. We hope estimates will be provided prior to the public consultation on the second draft of the PIP assessment.

8.4 The Government has also failed to assess how other passported benefits will be affected by DLA/PIP changes. This was a recommendation by disability and carers' organisations for the 1,000 trial PIP assessments which G4S is currently undertaking for DWP. DWP sadly chose not to investigate the potential knock-on effect of losing DLA which suggests an indifference to how changes may affect families. We believe the potential effects must be fully analysed before final decisions are taken surrounding the PIP assessment process.

*The design of the PIP assessment, including: the assessment criteria and design; whether the assessment can objectively assess those with mental, intellectual and cognitive conditions and with fluctuating conditions; and the extent to which aids and appliances should be taken into account in the assessment*

9.1 The DBC and many of our individual members responded to the draft DWP assessment proposals. The DBC response is attached as appendix two.<sup>41</sup>

9.2 We are working with Government to try and improve plans and avoid repeating mistakes made when the previous Government introduced the Work Capability Assessment for Employment and Support Allowance. The DBC raised concerns as the WCA was being developed, many of which were ignored. The rush to introduce the PIP assessment may result in history being repeated.

9.3 The DBC is disappointed that our offer to assist in a day of trial assessments was declined by DWP. Our request to witness one of the trial assessments being undertaken this summer by G4S (or even a mock assessment) was also declined. This does not reassure disabled people that the new assessment is being developed in the most inclusive or transparent manner.

9.4 We remain unconvinced that a benefit designed to assist disabled people with higher costs of living is best served by an assessment process being developed to reduce the expenditure by 20% and focused on people with the "greatest needs". Nor are we convinced that the £675 million cost of reassessing DLA recipients to restrict support is the best use of limited public funds at a time of significant Government efforts to reduce the national deficit.

9.5 We welcome that the assessment is proposed to only take into account the aids that are normally used by an individual, rather than any that might potentially be available. However, it is important that those who require aids and adaptations still obtain points in the assessment to qualify for PIP. Use of aids accrues costs and can require financial assistance. For example, buying, charging and maintaining an electric wheelchair, fuelling and insuring an adapted vehicle or even feeding an assistance dog. We are very concerned that the current PIP assessment proposals ignore these issues of costs; DLA was introduced to help disabled people meet higher costs of living.

9.6 The National Rheumatoid Arthritis Society and other DBC members are very concerned about the impact of the changes on people with long term fluctuating conditions. The introduction of the PIP assessment test and plans to increase the assessment period for PIP to six months are likely to result in a disproportionately large number of legitimate DLA recipients having financial support withdrawn under PIP arrangements. People with arthritis experience flares that are extremely painful, highly unpredictable and debilitating, and which last for indeterminate periods of time for example. In its current form, PIP would be more difficult for these individuals to access because the proposed assessment does not take account of the importance of being able to undertake an activity repeatedly, reliably and safely—and without significant pain. More needs to be done to take into account the frequency, severity and duration of fluctuating conditions to reflect these issues and ensure this issue is addressed in Government plans.

<sup>41</sup> Information provided, not printed.

*The delivery of the PIP assessment, including: who should carry it out; the approach to tendering for the assessment contract; who should make the award decisions; whether there are lessons to be learned from the Harrington Review of the Work Capability Assessment; and interaction with other eligibility assessments*

10.1 The WCA process and Atos delivery of assessments have led to a 40% success rate of appeals against initial decisions. The cost to the Tribunals Service was £8 million last year (excluding Atos and DWP costs). An equivalently high successful appeal rate for PIP assessments should result in penalties to assessors (either individually if particular assessors show poor decision making abilities or collectively to the contractor). This should be built into the contract—as should the need for the assessment to be developed over time.<sup>42</sup>

10.2 Recently, a man found fit for work died whilst waiting to appeal a WCA decision.<sup>43</sup> This extreme case is the tip of the iceberg of poor decision making processes. The mistakes of the WCA process should be avoided and the DBC is most concerned about the human costs of unnecessary assessments.

10.3 The disabled people we represent often feel over-assessed for support from public services already and further stressful and intrusive assessments are likely to aggravate some conditions and cause distress and anxiety which is harmful for individuals, families, the NHS and a waste of limited public resources.

*How DLA/PIP should apply to children and people over the state pension age*

11.1 DWP has initiated discussions about how to include children in PIP as the next phase of DLA reform and implied, in a response to a Freedom of Information request, that older disabled people will face reform later too.

11.2 For DLA/PIP purposes, the Government defines people of working age as 16–64 years of age and people under working age as under 16. This risks failing to recognise the unique needs of young people in the welfare system and runs contrary to the Government's vision set out in the recently published SEN and Disability Green Paper for a coordinated system of assessment and support from birth to 25. The Government plans to raise the Participation Age in 2013 (to age 17) and 2015 (to age 18) which also presents a new transition point for young people and this should also be recognised in the benefits system. CLIC Sargent have advocated an abolition of working age DLA for 18–64 years of age for example (rather than 16–64 as proposed).

11.3 The DBC has previously supported older people's request for equity between the support available from DLA and Attendance Allowance (AA). We are concerned that PIP may offer less resources for disabled people and that any transfer of AA recipients into PIP after the under 65s have been "migrated" over will also result in reduced support for older people.

*The steps DWP needs to take to ensure that its reform proposals are clearly and effectively communicated to claimants and the general public*

12.1 The DBC is very concerned that DWP appears to take no responsibility for the distortion of its statistical releases on disability benefits issues despite a previous compact existing<sup>44</sup> and standards being required for reporting information. It is very disappointing that DWP takes no action to combat inaccurate reporting and negative stereotyping which some believe is linked to the increased incidence of disability harassment and abuse.<sup>45</sup>

12.2 Misuse and misreporting of statistics is unhelpful and raises disabled people's anxiety over the Government's motivation for cuts.

12.3 DWP has accused disability organisations of "scaremongering" in raising the concerns of disabled people. DWP must provide accurate estimates for the number of disabled people who will lose DLA through the introduction of PIP. DWP should identify the disabled people who could potentially lose out early not just to avoid inaccurate figures being used, but to ensure people are written to at the earliest juncture to explain:

- the Government rationale for reform;
- the timeframe for re-assessing DLA recipients;
- the assessment process; and
- the appeals process for disabled people who believe there needs are high enough to warrant eligibility for PIP.

12.4 It is also very important that DWP engages with DLA recipients as it approaches the consultation on the second draft of the PIP assessment to ensure that the views of the disabled people most affected by the changes are heard, concerns addressed and risks mitigated.

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<sup>42</sup> The DBC supports the recent, similar recommendations made by the Work and Pensions Select Committee.

<sup>43</sup> See: <http://www.guardian.co.uk/society/2011/jul/24/atos-case-study-larry-newman> for further information. Other examples of disabled people inappropriately found fit for work are highlighted in the Parkinson's UK report: *Of little benefit and not working* 2009. See: [www.parkinsons.org.uk/pdf/esareport\\_october2009.pdf](http://www.parkinsons.org.uk/pdf/esareport_october2009.pdf)

<sup>44</sup> The DWP Stakeholder Forum agreed, for example, that DWP communications aimed at a lay audience (including media outlets) would be explicit as to the meaning of phrases like "fit for work" to avoid stigmatising and inaccurate interpretation.

<sup>45</sup> Scope reported a recent rise in harassment; see: [www.scope.org.uk/news/matthew-parris-and-times](http://www.scope.org.uk/news/matthew-parris-and-times)

*Transitional arrangements*

13.1 The DBC believes there are many disabled people who could be transferred to PIP without the need for costly and bureaucratic reassessments. Disabled people with evidenced needs and receiving the highest levels of DLA care and/or mobility, people with long-term, degenerative conditions or impairments evidenced to have high associated costs are examples of people who could have transitional arrangements made to prevent unnecessary expenditure on assessments.

13.2 The Government could also benefit from providing disabled people with complex conditions with transitional arrangements rather than have to ensure assessment centres are all trained in rare conditions.

2 September 2011

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**Supplementary evidence submitted by the Disability Alliance**

Thank you for the chance to provide evidence to your inquiry into the Government's planned DLA changes. You asked if there were further points the panel would like to make and there were several areas arising from your questions which I would like to provide additional information on for the Disability Alliance.

We hope Committee members are aware of our role in tackling poverty and supporting disabled people, their families and advisors. We welcome you and/or your constituency associations joining Disability Alliance and taking advantage of the support we can provide you and your staff in answering complex welfare, benefits and other support enquiries for your constituents. We currently have over 370 member organisations across the country including over 40 councils.

1. *How many disabled people could lose out?*

Committee members asked specifically about the role of Disability Alliance in this area as we have attempted to provide estimates for winners and losers under DLA/PIP plans. At Disability Alliance we are proud of our efforts to tackle disability poverty and mindful of our charitable obligations to uphold our work and campaigns in this area. We are very concerned that the Government has not yet provided an accurate estimate for the number of people who could lose support under plans to abolish DLA for people 16–64 years of age.

In 2010 the Treasury predicted 360,000 disabled people could lose help by suggesting a 20% cut in "resources and caseload" (with total 2010 working age caseload being 1.8 million). This figure was quickly dropped by DWP. However, the consultation on introducing PIP and delivering the target cut in expenditure by 2015–16 focused on targeting resources at "those with the greatest needs" and Government plans include providing just two levels of "Daily Living" under PIP (as opposed to the three levels of "care" support under DLA). We believe the language used on "highest needs" and the abolition of low rate care, coupled with the savings target, make it highly likely existing DLA low rate care recipients are very much at risk of losing support under PIP.

652,000 disabled people aged 16–64 currently receive this £19.55 per week level of support and if all lose every penny of help the total annual saving would be £663 million annually; the target is £1.3 billion a year. We expect more disabled people will lose out and DWP are unable and/or unwilling to deny our estimate is accurate. This makes it unlikely the Department can justify it has met its obligation under the Equality Act to adequately impact assess proposals.

After denying the Treasury estimate was accurate, DWP committed to re-estimating how many disabled people could lose help. The sample tests of 900 people involved over the summer in 2011 were supposed to provide information on who could lose support. We were told estimates would be available with the second draft assessment which was published on 14 November. Figures were not included. This is hugely disappointing and intensifies the anxiety disabled people and their families are experiencing over Government plans. It is worrying that, whilst the Government accuses charities of being misleading, if estimates are incorrect, DWP has had ample time and opportunity to ensure alternative figures were provided. DWP has chosen not to do so and we hope your Committee will request DWP act quickly to address this vacuum rather than attempt to portray charities fulfilling their legitimate role (as an important part of the Big Society) as somehow unhelpful.

Making accurate predictions: the contributions based ESA estimate

Whilst we wait for DWP to provide an estimate, the Committee may appreciate being aware of some recent history in predicting the impact of cuts in support to disabled people. In 2010 the Government announced a 365 day time limit for people receiving contributions-based Employment and Support Allowance (ESA—to be delivered by the Welfare Reform Bill and implemented from April 2012). Disability Alliance estimated this would require 400,000 disabled people to lose support to help meet the savings target of £2 billion. These disabled people (all will have received 15 points or more in the stringent Work Capability Assessment) and all have previously worked and made National Insurance contributions. DWP accused Disability Alliance of inaccuracy and the Minister for Disabled People, Maria Miller MP, told our conference in November 2010 that no one would lose out.

Whilst a means-tested alternative does mean DWP estimate 60% of the people who lose help will receive income-based ESA instead, the savings are only possible from disabled people losing support. In December 2010 the Minister told the House of Commons that about 325,000 could lose all out of work help. This only included existing recipients. DWP has now suggested over 700,000 disabled people will be affected, with 40% losing all out of work support.

Disability Alliance is a small charity but appears, on ESA, to have provided a far more accurate assessment of how many disabled people could be pushed further into poverty than the lead Government department. On DLA we believe our estimates will sadly also be closer than the Government may be willing to acknowledge.

#### DWP accuracy and robustness on DLA

The inaccurate initial DWP estimates for the disabled people in care homes who could lose support under further DLA changes (ending eligibility for care home residents) also makes the Government's approach to DLA cuts less convincing. When the cut was announced for care homes, DWP suggested 55,000 could lose help. The figure was upped to 78,000 when properly analysed. We are very pleased the Government has now dropped this policy—an area we campaigned on and are very grateful for the change of heart. We are concerned that DWP must now make the £160 million cut this policy was intended to provide in broader DLA/PIP changes. More than 44,000 disabled people would need to lose average DLA payments (£70 per week) to meet an additional £160 million target.

DWP has sadly not demonstrated absolute competence in ensuring estimates are robust to date and we hope you will press for any estimates for the final DLA losses to be better analysed.

#### 2. A potential legal challenge to PIP plans

Committee members also asked about the Disability Alliance's warning to DWP that plans may not meet Equality Act obligations to "promote equality of opportunity" for disabled people or carers (who are mostly women, making the concern one of gender equality).

We issued our warning in July based on a survey of our members' views (with 98% of respondents in support) and a Board of Trustees' unanimous decision.

Our concerns focused on the lack of analysis of the impact of the cuts and were based on a year of fruitless dialogue with DWP. More than 5,500 people responded to the Government consultation and over 1,750 responded to the Disability Alliance survey on the issue. This achieved no change at all in Government plans and secured no answer to legitimate questions raised. The lack of Government attention to disabled people and their organisation's questions and concerns, including those raised by Disability Alliance, was a significant frustration across the sector and for hundreds of thousands of people (if not the full 2 million working age DLA recipients). Issues raised included the disabled people who told us and DWP that without DLA their lives may not be worth living. The serious nature of concerns and the Government's lack of responsiveness also led to a letter of complaint from the seven largest disability charities to the Prime Minister and Secretary of State for Work and Pensions. It is believed this had never occurred in the albeit relatively short history of the role of the Minister for Disabled People (which was supposed to ensure disabled people had a voice in Government). Disability Alliance's warning of potential legal action if concerns remain unaddressed should be seen in this context.

Disability Alliance is more than happy to provide Committee members with a copy of our letter of claim, associated Freedom of Information request, and the DWP response. These are online and we genuinely hope the Government will address concerns and ensure disabled people's equality of opportunity is enhanced and we do not need to enter full legal action.

DWP suggest that more disabled people will enter work as a result of DLA/PIP plans and that this will mean an increase in equality of opportunity. Whilst Disability Alliance works to support disabled people into work (as one essential route out of poverty) we are concerned at:

- the lack of evidence for this assumption (DWP research reports—and more independent work—is inconclusive on DLA being a barrier to work);
- the contradiction of emphasising this approach in response to our letter of claim compared with the alternative, public narrative about PIP being designed as an improvement on DLA;
- the number of disabled people, particularly those on low rate care DLA, who could be forced out of employment (or to reduce working hours) if they lose support under PIP plans (as highlighted by disabled people in more than one survey);
- the limited employment available and apparent reduction in some forms of Government support for disabled people to get/keep work (eg reduction in numbers of disabled people receiving Access to Work help in the last financial year); and
- the lack of Government monitoring plans in this area if PIP is genuinely designed to ensure more disabled people enter work.

We could still request a full Judicial Review after the Welfare Reform Bill is enacted if our concerns remain unaddressed.



### 3. Use of DLA: estimating the impact of losing support

How disabled people use DLA is well-researched. It is not a huge jump to estimate how people will be affected by losing DLA or experiencing a reduction in support under PIP. A brief analysis is suggested below for ease of reference for Committee members.

#### Potential impact on poverty

Disability Alliance exists to fight disability poverty. A third of disabled people already live in poverty in the UK—40% of disabled children according to one recent Children's Society report.

Support for disabled people is in decline in some areas due to council budget tightening, health service changes and other benefits being withdrawn. DLA has been described as an "essential lifeline" by disabled people in several surveys. The Government plans will see further impoverishment and outright destitution for disabled people denied access to this lifeline of flexible help with higher costs of living. But the Government analysis of DLA cuts to date does not include who could lose out and how, including the risk to increasing disability poverty.

The trials undertaken by DWP have also failed, despite requests, to take into account the knock-on effect of losing DLA. DLA acts as a passport to alternative help, including Carer's Allowance, and DWP must take what has been described as the "domino effect" into account. Some disabled people's organisations have described the risk of losing DLA as having a "house of cards" effect on collapsing all support arrangements.

#### Potential impact on life

Disabled people have made clear to Disability Alliance and our member organisations that life is genuinely at stake for some of the disabled people affected. DWP research also highlighted that on suggesting losing £50 per week for DLA and Attendance Allowance recipients generated responses like "it would kill me" (DWP Research Report 649, 2010).

Disability Alliance is willing to share our full responses to our open questions in survey which elicited some disturbing statements on this issue with Committee members. We would need to make responses anonymous but the comments speak for themselves and should not be ignored by DWP in the rush to deliver a 20% reduction in expenditure by 2015–16 which allows little time to ensure the new assessment process is accurate, fair and effective at identifying needs.

In communicating the startling views and possible outcomes for some disabled people to DWP the Government has suggested scaremongering on the part of those organisations responsible for representing the people affected. We believe it is fundamentally irresponsible for the Government to ignore this issue.

Sweeping the issue under the carpet and sweeping aside legitimate concerns from independent advisors is beyond callous. Evidence of previous benefit cuts demonstrates the need to be sensitive to the impact on disabled people. The Benefits Integrity Project, for example, is associated with some deaths and was a far smaller programme.

To assume it is possible to remove support from thousands of disabled people without tragic, even if unintended, consequences demonstrates a lack of understanding of the difficult history in this area and a need to act with the utmost caution and responsibility.

#### Potential impact on (avoidable) NHS demand

One in eight of the respondents to our survey on DLA reform highlighted how their health could become unmanageable or decline with lower/no access to DLA/PIP. DLA helps pay for medication, alternative therapy, additional health needs unmet by the NHS and enables people to manage conditions, including mental health needs.

The impact of losing DLA could mean increased hospitalisation for people unable to manage health conditions and may be likely to cost significantly more than the £19.55 per week currently accessed by disabled people receiving low rate care DLA payments. The accepted figure for one night in hospital care is about £500, this is the equivalent of almost half a year (25 weeks) on low rate care DLA payments.

The new assessment process planned by DWP will also incur significant NHS resources. Two million people undergoing the new assessment will need to provide independent medical evidence from GPs and/or other consultants. It is unclear what costs are attached to this or if the Department of Health has planned for this additional cost/resource.

In the Lords stages of the Welfare Reform Bill, the Minister spoke of dialogue with Department of Health colleagues and it would be useful in Committee members pressed DWP to examine when DH was engaged and how the NHS is being prepared for PIP implementation—which is now just 15 months away.

## Potential impact on work

In responding to Disability Alliance's concerns over equality of opportunity, the Government has suggested more disabled people will enter work if DLA expenditure is cut. DWP suggest two DWP research reports from 2010 provide evidence that DLA is a barrier to work. The evidence is grey at best and the 2010 reports are inconclusive.

Given the DWP reliance on these reports to suggest a 20% cut in resources for DLA/PIP the section of DWP research report 649 is quoted at length below to demonstrate its lack of conclusiveness that DLA is a barrier to work (our highlighting in italics for emphasis):

DLA recipients well past state retirement pension age, and some younger people with severe conditions no longer saw any likelihood of doing paid work again. But *most people below state retirement age in this sub-group said they would like to be able to have a job, perhaps in the future when well enough to work*. Younger people claiming job seeker's allowance had been actively seeking work during the past six months and one person had just started a job when interviewed.

Those people, who thought about working or had looked for work had considered what might happen in respect of their DLA, and some had talked about this to partners. There was a range of perceptions.

There was some belief that DLA was an out-of-work benefit. One young man firmly believed that people did not get DLA if they worked. At the same time, he believed that he was not expected to seek work if he got DLA. His symptoms were such that he was currently some distance from paid work, and his current priorities were re-establishing medical treatment and support for a severe long-term condition.

An older couple, approaching state retirement age, also appeared to believe that DLA was an income replacement benefit and, as such, the recipient's partner argued it was not really equivalent to a basic wage. *Their belief was not influencing the recipient's thoughts about working, however, as poor health made this impossible*. The recipient's partner speculated that if they put Carer's Allowance into the equation, as this would also be lost if DLA was withdrawn, one or other of them would have to secure a very good wage for the couple to be better off in work than when claiming highest rate DLA and Carer's Allowance. But they emphasised that there was no prospect of either of them doing paid work—one needed intensive care and the other gave it. Another person who believed DLA would be withdrawn in paid work thought that there was now an in-work "Disability Working Allowance" which would partially compensate for loss of DLA. Again, however, such belief was not influencing behaviour because the person concerned was now too ill to work.

Although other people who thought about work knew they could continue to get DLA, there was some belief that DLA was earnings related. A young person who had been advised to "be careful" in choice of job so that DLA was not affected found it hard to remember in the research interview what this meant, but thought it probably meant it was better not to take more highly paid work.

There remain those people who sometimes thought about working, or had just taken a job and knew that DLA would continue to be paid. The "better-off calculations" which they had made took into account the expenses of working, the likelihood of low earnings capacity and, for some, the need to pay for more care and support to enable them to sustain work. For example, having even a part time job would mean, for one person, being too tired to do some of those things at home now managed on their own. The person who had just started work of 15 hours weekly had done careful calculations and was confident in being financially a bit better off. What might happen at the end of the year, when DLA review was due, was a concern however. If DLA was not awarded again, consequent reduction in housing benefits would mean being no better off than on Jobseeker's Allowance, with additional loss of some of the DLA "passports" that were important. For this person, withdrawal of DLA would seem a positive indication of recovery and a welcome move away from the idea of being "disabled". But the financial implications and constraints would be stressful and unhelpful. Past experience was that trying to use Working Tax Credit on variable earnings from short-term contracts and self-employed work—the likely future working pattern—involved a volume of reassessments, changes in income and uncertainties that would have negative impact on control of symptoms and recovery.

About one in five DLA recipients are in work. We hope the Committee inquiry will focus on how the Government ensures people in work can retain employment if they lose DLA. In our survey, of the disabled people in work more than half said they could be forced to reduce work hours or leave employment altogether without (or with less) DLA. Access to Work and other in-work support will not cover all higher costs of living disabled people experience—and can be less flexible in how they are accessed and/or able to be used. Employers are not obliged to provide work transport for example, and even Access to Work can prevent some disabled people being able to fund alternative transport.

We hope the Committee will be aware that even in work, disabled people earn less than non-disabled people but retain higher costs of living. It is essential PIP is able to support disabled people in work and does not result in higher unemployment for disabled people.

### Potential impact on (avoidable) social service demand

Some disabled people and families told us without DLA (or with less DLA) that greater demand would be created for council provided social care services. Many people highlighted the likelihood that residential care might be required if families could not support disabled people at home. Comments to open questions included:

“I would not be able to provide for my wife’s needs at home, her quality of life would be greatly decreased, Pamela would probably then need to go into a care home—this would be her worst nightmare and would probably make her SUICIDAL.”

“I would become housebound and very possible have to go into a care home. The current uncertainty is having a very bad effect on my mental health and has totally destroyed my peace of mind.”

“I’m probably going to die or at least become very unwell and end up in a care home or hospital 24/7—what sort of a life is that?”

“no doubts about he would have to go into council care home, his mother died early in life looking after him, I do not intend to go the same way, if payments reduced no alternative.”

“Our whole life would have to change probably resulting in our daughter having to go into a care home.”

Councils do not have resources to meet higher demand for support from care services. Many councils have severely restricted access to care services. More than 80% of England councils now only provide support to disabled people with “critical” or “substantial” needs. DLA has provided the last line of help for many disabled people unable to access formal social care services. People with mental health problems in particular have found accessing sufficient care service support difficult and any growth in DLA use under the main “primary disabling condition” being mental health needs should be no surprise to Committee members familiar with the broad care funding crisis and growth in informal care provision by family members.

The care crisis has led to political leaders focusing on how to fund care services. The Dilnot Commission provided the latest tranche of evidence suggesting the need to reform and better fund care. What is often overlooked by DWP is that Dilnot concluded that:

“Universal disability benefits for people of all ages should continue as now.”

DWP and broader Government ignore this recommendation at cost. Losing DLA as a universal source of support for disabled people will result in higher care needs and a lack of ability to manage health conditions/ impairments by disabled people and broader families. We hope the Committee will examine this issue in more detail with the Minister. We believe the role of the Department for Communities and Local Government and direct local authority representatives has been significantly overlooked in this area. Your questioning about how DCLG and COSLA/LGA have been engaged (for example) would be very welcome.

### *Final consultation/trial plans*

Members of the Committee also asked about DWP consultation plans. DWP have confirmed that the plans are to hold a formal, public consultation from early 2012 for about 13 weeks (ie longer than the recommended time frame). This is welcome. We will, with our members and more than 50 partners of the Disability Benefit Consortium, be responding and remain committed to trying to improve Government plans to exact the best possible outcome for disabled people.

DWP have tested the draft assessment on 900 people. It is unclear if this is all disabled people or what impairment groups are covered. DWP have suggested that there will be no further in-depth trialling of the new assessment (despite it being redrafted) before full implementation. This is very alarming. It is doubtful that this sample is strong enough to ensure the 2 million people currently receiving working age DLA support will have confidence in any new assessment process from 2013.

DWP have yet to indicate how the amendments to the initial Government plans would impact on the 900 people already tested, aside from the broader 2 million people who will need to be reassessed for PIP from April 2013. DWP have also failed to examine the knock-on effects of losing DLA on other support and on disabled people’s families.

We would welcome a commitment to trialling the new assessment on new PIP claimants from 2013 and a staggered approach to transferring disabled people from DLA to PIP (or off support altogether). Given the history of the Work Capability Assessment it is essential the assessment is effective at identifying needs and able to adapt quickly to improvements. Given the indecent timeframe the Government is working to it is unlikely a perfect system will be ready in 15 months. Allowing a trial period and the ability to bring disabled people over by impairment groups or other classifications (eg age) would offer some reassurance that the Government is aware of potential challenges and able to operate the new benefit as sensitively as possible.

### *Concluding comments*

Overall, we do not believe DLA/PIP reform—as currently proposed—will enhance disabled people (or carers’) equality of opportunity.

DWP continues to fail to analyse the potential impact and does not appear to have engaged Department of Health and Department of Communities and Local Government in assessing the likely increase in demand for

other government services. We hope the Committee will press DWP to ensure its analysis is robust and that no unexpected costs to the NHS or councils arise from removing access to direct support for disabled people.

We believe DWP has an essential role to play in supporting disabled people. If the Government's defence in cutting projected DLA expenditure is that it will mean more disabled people will enter work it would be useful to hypothecate resources from the cut for Access to Work for example (or other support for disabled people to get and keep work). It would also be welcome if the Committee examined the Government's plans to monitor implementation of the abolition of DLA for their impact on disabled people entering work.

7 December 2011

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**Written evidence jointly submitted by the Royal National Institute of Blind People (RNIB), Action for Blind People, Guide Dogs, Sense, Visionary, National Blind Children's Society, SeeAbility and the National Federation of the Blind (PIP 35)**

1. INTRODUCTION

1.1 The Government is to replace Disability Living Allowance (DLA) with Personal Independence Payment (PIP). We responded in detail to the White Paper<sup>46</sup> and to the draft regulations.<sup>47</sup> We are closely engaged in further discussions with officials.

1.2 While these discussions are generally constructive in tone, we are concerned that the requirement to make over £1 billion in savings circumscribes them. This will prove an obstacle to developing a benefit that properly meets the needs of people with visual impairments.

1.3 In this submission, we have focused on those issues in which the Committee has expressed a particular interest, with an emphasis on those where we have had strong feedback from blind and partially sighted people.

2. SUMMARY

2.1 Although reassessment and revised criteria are not wrong in principle, experience shows that consequences detrimental to vulnerable people can occur when the process is driven by a "cuts" agenda.

2.2 Our evidence shows that DLA is a key support to independent living. Any new assessment must reflect this.

2.3 PIP provides an opportunity to address how *communication* and *accessing information* are dealt with in seeking to reflect the extra costs of disability. Communication difficulties are particularly important for blind, partially sighted and deafblind people, involving distinctive issues. There is a strong case for introducing "communication" as a third component within PIP. Alternatively, communication must be much more explicitly recognised within the assessment process for the proposed dual component structure.

2.4 PIP claimants need to prove both initial and ongoing eligibility. Periodic reviews facilitate this, but should be realistically scheduled to reflect the likelihood of change in circumstances and condition.

2.5 The focus on those "who face the greatest day-to-day challenges" threatens eligibility at levels of disability that currently qualify. It fails to recognise the extra costs of conditions that are long-term without being at the highest end of severity; and the preventative role of financial support at that stage. The impact and implications of sight loss are also systematically underestimated.

2.6 The move to two "daily living" rates seems to be a device to abolish the lowest rate of the current care component, pushing many out of entitlement.

2.7 DLA (and by extension PIP) plays a different role to social care, contributing to prevention rather than duplicating funding—as the Dilnot report recognises.

2.8 The threat to PIP (mobility) for people in residential settings is a worrying hazard to independent living, rather than reflecting any real funding overlap.

2.9 Ending automatic entitlement, including the higher mobility component for people who are deafblind or severely visually impaired, would be a retrograde step, not only introducing uncertainty for claimants, but removing an administratively straightforward process from a small number of well-defined groups. This runs counter to wider efforts to streamline benefit administration.

2.10 Indefinite awards should continue to be made if a condition is unlikely to change.

2.11 We cannot see the justification for doubling (if the claimant is not terminally ill) the qualifying period before a claim can be made. If PIP is to enable greater independence, the earlier it is paid the more likely it is to succeed. The proposal will have a particularly negative impact upon those with sudden onset conditions or

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<sup>46</sup> *Disability Living Allowance review: a joint submission from the visual impairment sector*, 11 VI sector organisations, February 2011. Updated as an RNIB briefing, April 2011.

<sup>47</sup> *The proposed Personal Independence Payment: the draft regulations—key issues for blind and partially sighted people*, 9 VI sector organisations, June 2011.

impairments. This issue emphasises the need for good-quality reablement support and also rehabilitation services, promptly delivered, for those who would benefit from them.

2.12 “Passport” links must be protected. They assist take-up and save administrative expense. They also show how failure to qualify for PIP—or delay in qualifying—would often have serious knock-on effects.

2.13 Assessors should seek specialist guidance regarding fluctuating conditions. What matters is that the condition, although variable, is ongoing.

2.14 Claimants may stand to lose a lot of money by exploring available aids and adaptations—a perverse dilemma. These should be regarded as complementary to benefit entitlements, not in competition with them.

2.15 It is unclear what relative weights will be attached to the different sources of information involved in the assessment process. Relevant professional skills should include rehabilitation.

2.16 Due weight should be assigned to a degree of self-assessment as an input to evidence-gathering, as well as involving others such as family members and carers.

2.17 The Harrington review of the Work Capability Assessment (WCA) has lessons for PIP: Department for Work and Pensions (DWP) decision makers must retain responsibility for making or reviewing awards; more decisions should be correct first time; assessments must be centred on the claimant’s needs; the process should be explained in advance, with an opportunity to present medical evidence and talk about the functional impact of a visual impairment; assessors should have at least a basic understanding of single and dual sensory loss; the assessment report should be transparent; and a uniform assessment relying heavily on software should be avoided.

2.18 There are possibilities for co-ordination of PIP claims and social care assessments, as long as this does not lead to the latter becoming a required gateway to the former, confusing roles and inhibiting PIP take-up.

2.19 A child’s needs can increase, for example as a disabled child gets older, so a planned review mechanism will be necessary for certain conditions. But routine reassessment of children would be potentially disruptive. Meanwhile, careful consideration must go into the transition to PIP of existing DLA claimants on reaching 16.

2.20 Those receiving DLA before age 65 continue to be entitled beyond that age, if they continue to meet the conditions. This must be carried over into PIP.

2.21 The Government should proceed carefully when introducing new assessments. Explanations, to the media and the public at large, must be clear and handled sensitively. The many problems with the WCA included poor communication.

2.22 The numbers losing from the change should be kept to a minimum and existing claimants given transitional protection.

### 3. THE DWP PROPOSALS AND OUR CONCERNS

3.1 The DWP plans to introduce PIP in 2013–14, when they will begin reassessing the working age (16–64 year-old) caseload.

3.2 Reassessment and revised criteria are not wrong in principle, but the experience of Incapacity Benefit and Employment and Support Allowance has shown us that consequences detrimental to vulnerable people can occur when the process is driven by a “cuts” agenda.

3.3 Our evidence to the Green Paper and draft regulations consultations shows how DLA plays a vital role for blind and partially sighted people, enabling them to have greater personal choice and more independent lives. Any new assessment must highlight effectively the needs of and barriers faced by blind and partially sighted people, identifying the consequent requirements for additional income.

3.4 We address below the particular areas of interest set out in the Committee’s call for evidence.

### 4. THE NEED FOR DLA REFORM

4.1 This consultation has given the sight loss sector the opportunity to take stock of the enablers and barriers to independent living experienced by blind and partially sighted people. One issue that has crystallised is how poorly issues of *communication* and *accessing information* are dealt with in assessing the extra costs of disability.

4.2 Communication difficulties are particularly important for blind, partially sighted and deafblind people, involving distinctive issues. We believe that there is a strong case for introducing “communication” as a third component within PIP. We have offered to discuss in detail with the DWP how such a component might operate.

4.3 Alternatively, communication must be much more explicitly recognised within the assessment process for the proposed dual component structure. Again, we would be happy to discuss with the DWP how the concept of communication (with all its facets) could be integrated in this way.

4.4 There will be periodic reviews under PIP. A review can lead to an increase or decrease in, or loss of benefit, where a condition has changed. Issues around the quality and fairness of initial assessments will doubtless apply to reviews also.

4.5 PIP claimants need to prove both initial and ongoing eligibility. Periodic reviews facilitate this, but should be realistically scheduled to reflect the likelihood of change in circumstances and condition. Sight loss is usually a deteriorating condition and the system needs to be sensitive to this, to identify where needs may have changed but not constantly review where there is unlikely to be any change—risking waste of public money and undue distress to recipients.

## 5. THE IMPLICATIONS OF A REDUCTION IN EXPENDITURE

5.1 The focus on those “who face the greatest day-to-day challenges and who are therefore likely to experience higher costs” threatens eligibility at levels of disability that currently qualify, especially for the lowest rate of the current care component. It fails to recognise the extra costs of conditions that are long-term without being at the highest end of severity. It also fails to recognise the preventative role of financial support at that stage—helping to avoid premature need for more intensive, including residential, care. It is clear from our consultations with blind and partially sighted people that this is how they use their DLA—to secure such lower level, preventative support.

5.2 The impact and implications of sight loss are also systematically underestimated in assessing the challenges a claimant faces.

5.3 There will be two components of PIP: “mobility” and “daily living”, each with two rates. This seems to be a device to abolish the lowest rate of the current care component, pushing many out of entitlement and relating solely to the savings target.

## 6. THE EXTENT TO WHICH OVERLAPS IN FUNDING EXIST

6.1 Politicians of all parties have acknowledged, in the social care debate, that it would be counter-productive to subsume disability benefits into social care funding. DLA/ PIP, as noted above, can play a preventative role in helping to avoid premature need for major social care interventions—as the Dilnot report on social care and support funding recognises.

6.2 As regards the threat to DLA/ PIP (mobility) for people in residential settings: the Government is now “reviewing existing and gathering further evidence to inform how best to proceed”.

6.3 This represents progress, but continued vigilance will be required. The original proposal would seriously increase the risk of social exclusion and isolation for blind and partially sighted people in residential care who use DLA (mobility) for example to meet taxi fares to visit relatives, or the travel costs of an escort. LAs have no specific statutory duty to meet such costs and in present financial circumstances it is fanciful to suppose that they would be generally likely to do so.

## 7. AUTOMATIC ENTITLEMENT

7.1 People with certain health conditions or impairments currently have automatic entitlement to specified DLA components. The DWP proposes to end this, every case (except for people who are terminally ill) requiring separate assessment.

7.2 This would end automatic entitlement for people who clearly ought to have it, including the higher mobility component for people who are deafblind or severely visually impaired. This would be a retrograde step, not only introducing uncertainty for claimants, but removing an administratively straightforward process from a small number of well-defined groups. This runs counter to wider efforts to streamline benefit administration.

7.3 It would also make sense to continue to make indefinite awards if a condition is unlikely to change.

## 8. SIX-MONTH QUALIFYING PERIOD

8.1 Claimants “will have to qualify for the benefit for a period of six months and be expected to continue to qualify for a further six months before an award can be made”.

8.2 This doubles the qualifying period before a claim can be made, if the claimant is not terminally ill—in effect, delaying payment of benefit by three months. We cannot see the justification for this, other than simply cost-cutting. If PIP is to enable greater independence, the earlier it is paid the better—supporting reablement and mobility and protecting against isolation.

8.3 The proposal will have a particularly negative impact upon those with sudden onset conditions or impairments.

8.4 This issue emphasises the need for good-quality reablement support and also rehabilitation services, promptly delivered, for those who would benefit from them.

## 9. PIP AS A GATEWAY TO OTHER BENEFITS

9.1 DLA is linked to qualification for other benefits and premiums (as well as exemption from the proposed benefits “cap”). It also acts as a passport to other services and concessions, including the concessionary travel, Blue Badge and Motability schemes.

9.2 These links must be protected. They assist take-up and save administrative expense. They also show how failure to qualify for PIP—or delay in qualifying—would often have serious knock-on effects.

## 10. THE DESIGN OF THE PIP ASSESSMENT

10.1 We have commented above on the need for assessment criteria to address much more adequately issues of communication and accessing information and other challenges presented by visual impairment. We have explored these questions in detail in our response to the draft regulations<sup>48</sup>

10.2 Assessing fluctuating conditions is difficult and is relevant to some visual impairments—for example, nystagmus; or those where sight loss arises from a condition such as multiple sclerosis where vision can vary from day to day. Assessors should seek specialist guidance. What matters is that the condition, although variable, is ongoing.

10.3 PIP will “take greater account of aids and adaptations”. Claimants may stand to lose a lot of money by exploring available aids and adaptations—a perverse dilemma. These should be regarded as complementary to benefit entitlements, not in competition with them.

10.4 Often, people have to buy aids and adaptations themselves and many are extremely expensive.

## 11. THE DELIVERY OF THE PIP ASSESSMENT

11.1 Evidence-gathering will involve “information from the individual, as well as healthcare and other professionals who work with and support them (and) advice from an independent healthcare professional”. This is designed to achieve “an objective assessment of individual need”.

11.2 It is unclear how this will work and what relative weights will be attached to these different sources of information. Relevant professional skills should include rehabilitation.

11.3 Due weight should be assigned to a degree of self-assessment as an input to evidence-gathering, as well as involving others such as family members and carers.

11.4 The Harrington review of the WCA has lessons for PIP:

- Ultimately, decision making must sit with DWP decision makers, not independent healthcare assessors. DWP decision makers must retain responsibility for making or reviewing awards.
- More decisions need to be correct first time. Clear guidance should be provided to assessors. Not only is poor decision-making undesirable in itself, but it tends to generate large numbers of appeals, a high proportion of which will succeed—an unproductive use of administrative resources.
- The face-to-face assessment must be centred on the claimant’s needs. The process should be explained in advance and they should have an opportunity to present medical evidence and talk about the functional impact of living with sensory loss. Assessors should have at least a basic understanding of single and dual sensory loss.
- The assessment report should be transparent.
- A uniform assessment relying heavily on software should be avoided.

11.5 The DWP will consider how PIP “interacts with other forms of support, for example adult social care, and explore whether it is possible to share information at the assessment stage and eliminate areas of overlap”.

11.6 This could have more than one meaning:

- A positive interpretation would be that local authority (LA) social care assessments should include a benefit check, with an automatic claim where entitlement appears to exist. Some LAs already do this, covering all relevant benefits. Where the benefits or services concerned cross administrative boundaries, the claimant’s/ service user’s permission should be sought.
- A different interpretation (which we hope is not intended) might be that social care assessments should become the only gateway to PIP. This would place a major strain on the social care assessment system, while adversely affecting the take-up of PIP.

## 12. CHILDREN AND PEOPLE OVER PENSION AGE

12.1 The DWP is considering whether and when to reassess children and DLA claimants aged 65 and over.

12.2 This could build unpredictability into the finances of families and individuals who need stability to plan for the future requirements of disabled children; or for their retirement years when future earnings are not in prospect.

<sup>48</sup> See footnote 24.

12.3 Needs can increase, for example as a disabled child gets older, so a planned review mechanism will be necessary for certain conditions. But routine reassessment of children would be potentially disruptive.

12.4 Meanwhile, careful consideration must go into the transition to PIP of existing DLA claimants on reaching 16.

12.5 As regards the 65+ age group, the current arrangement whereby those receiving DLA before age 65 continue to be entitled beyond that age (if they continue to meet the conditions) must be carried over into PIP. We are pleased to note that this is intended.

12.6 If reassessment of the 65+ age group is introduced, any deterioration of that person's condition should be recognised by permitting movement to the higher rate of any component, including mobility.

### 13. COMMUNICATION WITH CLAIMANTS AND THE GENERAL PUBLIC

13.1 The Government should proceed carefully when introducing new assessments. Explanations, to the media and the public at large, must be clear and handled sensitively. The many problems with the WCA have included poor communication.

### 14. TRANSITIONAL ARRANGEMENTS

14.1 The numbers losing from the change should be kept to a minimum and existing claimants given transitional protection from immediate financial loss.

### 15. CONCLUSIONS

5.1 We have set out above some of our main concerns and suggestions in the areas which the Committee has indicated are of most interest.

5.2 We have also provided in hard copy our previous submissions to the DWP in response to the White Paper and draft regulations,<sup>49</sup> containing a great deal of further evidence.

5.3 We should be happy to provide further information on request.

2 September 2011

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## **Supplementary evidence submitted by the Royal National Institute of Blind People (RNIB)**

### **PERSONAL INDEPENDENCE PAYMENT: SECOND DRAFT OF ASSESSMENT REGULATIONS**

- In May 2011 the Government published its initial proposals for the criteria to be used in the assessment for Personal Independence Payment (PIP).
- The Government consulted on its proposals over the summer. Over thirty blind and partially sighted volunteers participated in the testing of the initial assessment.
- There will be a formal consultation once the Department for Work and Pensions (DWP) has firmer views on the weightings of different “descriptors” within the assessment. We eagerly await more details on the scoring thresholds a claimant needs to meet to determine eligibility for PIP. Without these scores it is hard to comment on the revised regulations.

### 1. RNIB'S REACTION

The Government has started listening to blind and partially sighted people and the organisations that represent people with sight loss. However, the draft regulations still need considerable work. The Government wants to develop criteria which are clear to understand and apply and are consistent in their outcome. We are not yet satisfied the assessment will lead to clear or consistent outcomes for blind and partially sighted claimants.

#### *Positive developments*

Blind and partially sighted people face a wide range of barriers to independent living, so we welcome the introduction of descriptors around communication and social engagement. The revised criteria reflect a more sophisticated understanding of the support that blind and partially sighted people and other disabled people need to participate in society.

#### *Problems*

A number of the activities give insufficient attention to the barriers experienced by blind and partially sighted people.

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<sup>49</sup> See footnotes 23 and 24.



In addition, RNIB remains concerned about the potential effect of cutting the budget. *There is still a risk that significant numbers of visually impaired people and other disabled people will be ineligible* under Personal Independence Payment. Whilst we believe the revised criteria are an improvement, the key issue of where the eligibility cut off is made is still unclear. We have to suspend final judgement on the criteria until we learn more about how the assessment will be carried out, how the descriptors will be interpreted, and crucially, the thresholds for eligibility.

We also want the DWP to publish more details on the second round of testing that took place in the summer. The second round of testing—involving the second draft of the assessment criteria—gave rise to fewer concerns about their validity and reliability. Without this information we can only speculate why the Government believes this to be the case.

## 2. KEY ISSUES FOR BLIND AND PARTIALLY SIGHTED PEOPLE

### (a) *Additional costs*

- The DWP has rejected the idea of assessing the wider social, economic and environmental costs a claimant faces. It must still make sure the assessment addresses the additional costs borne by disabled people in terms of maintaining and buying new aids.

### (b) *Aids and adaptations*

- *We are not convinced the needs of long cane users are fully reflected in the revised criteria.* The Government has taken welcome measures to acknowledge the needs of guide dog users. However, someone who uses a white stick or indeed many other aids may still experience the penalising effect of achieving a lower overall assessment score.
- *We are concerned to see a reference to aids and adaptations that may “reasonably be used”.* RNIB is not convinced this will always produce fair outcomes so we would like the definition to be opened up to ongoing consultation with all the relevant parties.

### (c) *Assessments*

- The draft regulations explain what constitutes a good reason for failing to attend a consultation in person or by telephone, but this must be fault-proof.
- We do not believe that seven days is a sufficiently long period of time for communicating with claimants on attendance. When the criteria were tested with individuals this summer, we heard reports of individuals not being contacted via a communication method that is accessible to them, despite it being made very clear to DWP and the assessment agency what this method of contact should be. This must specify a time frame for checking with the claimant whether they were able to access the information they were sent and what stopped them from attending.

### (d) *Daily living activities*

#### General observations

- The draft criteria represent a more considered attempt to address the full range of barriers that visually impaired claimants' experience. We can begin to see how partially sighted claimants might score points under a range of daily living activities. However, we remain uncertain what threshold someone would need to meet to prove eligible for the standard and enhanced rates of the daily living component.
- Crucially, the key issue of whether a claimant scores points or not rests on how various descriptors are interpreted and whether guidance is clear enough for them to be consistently applied. Being blind or partially sighted presents serious barriers across a number of these activities, so for instance seeing to make financial decisions about buying food and grooming (shaving safely and effectively). RNIB understands this but we fear a number of the activities have been defined too narrowly for blind and partially sighted people to score points. We also have some concerns about the weightings that have been applied so for instance descriptor (d) in activity (7) on assistance to access written information attracts too few points.
- As with DLA now, we suspect most people with a visual impairment would only be able to claim the standard (or lower) rate of this component.

#### Assistance

- RNIB questions why “assistance” has been defined to mean you need a “physical intervention” from another person. Assistance to manage medication or monitor a health condition, to take just one example, ought to include the products or aids an individual needs to safely and reliably take medication, so for example, the need to store pills in a pill box.

#### Bathing and grooming

- It is a step in the right direction that washing, bathing and grooming are no longer assessed as being only just above a level of personal neglect. However, *we still think there are issues with the limited definition of grooming, which should include shaving and also other aspects of physical appearance.* Blind and partially sighted people may need assistance with cutting their nails. Being able to colour co-ordinate your clothes and check whether your clothes have tears present additional barriers to people with sight loss, but activity four has been defined too narrowly to encompass this.

#### Communicating

- *It is pleasing to see a broader definition of activities, which now include engaging socially and making financial decisions.* It was important to RNIB and other sensory loss organisations that DWP split the activities on expressive and receptive communication (so the criteria looks at someone's ability to communicate separately from their ability to access written information).

#### Planning and buying food and drink

- As regards planning and buying food and drink, we understand the intention is to accommodate this within the activity on making financial decisions. There might be some merit to this approach but only if it takes into account the barriers presented by not being able to see prices on food and drink when they go shopping.

#### (e) Mobility activities

- RNIB is pleased the DWP has removed the need for people to plan or follow a journey “only with continual prompting or intermittent assistance”. The way “continual” and “intermittent” were originally interpreted did not effectively describe how journeys were undertaken. People living with sight loss may need supervision or assistance but not necessarily throughout or for half the time it takes to complete an activity.
- The DWP has removed the references to simple and complex journeys and replaced these with RNIB's preferred concepts of “familiar” and “unfamiliar” journeys. This provides a more effective basis for assessing whether a visually impaired person has limited or severely limited abilities to carry out mobility activities. Blind and partially sighted people often experience difficulties with planning and following unfamiliar journeys, especially if it involves negotiating hazards or changing modes of transport.
- It is noticeable that the two mobility activities are the only two out of all 11 activities where it is proposed you might automatically score 15 points, thereby guaranteeing access to the enhanced rate. Although this is still a working draft, the criteria state that if you need a support dog to follow a journey to a familiar destination, then you may score fifteen points. The effect of this, or so it appears, would be to open up the enhanced rate of the mobility component to the vast majority of guide dog users. *However, we still don't know the full impact of these descriptors for people who use aids like long canes.*

#### (f) Need for support

- The time frame in which a claimant would need to prove limited ability to complete an activity has been revised. There is a focus on individuals who are consistently least able to carry out the activities. The assessment now considers the impact of disability experienced on the “majority of days” (more than 50%) rather than the “majority of the time”.
- This is a complex judgement to make especially when a claimant has a fluctuating condition. *The regulations and associated guidance will need to be really clear so claimants experience consistent outcomes.*
- The definition of “supervision” within the revised criteria is problematic. With DLA, supervision must be “continual” and there is case law about how “continual” is less than “continuous”. Continuous means uninterrupted, whereas continual means frequently reoccurring. With the new definition it will be more difficult to show a person needs supervision.

#### (g) Visual impairment

- The DWP is keen not to adopt a medical-based approach to assessing eligibility for PIP. The Government wants to find out how an individual's impairment affects them on a case-by-case basis. *We are not entirely convinced they have achieved this so for example some activities still appear focused on claimants with particular impairments.*
- Nonetheless the revised set of criteria makes a better attempt to assess the functional impacts of living with sight loss, not just in obvious areas like planning a journey but across many of the activities within the new assessment. We are particularly pleased the criteria make explicit references to “support dogs” and the need for such dogs to help complete journeys.

- We remain very concerned, though, that automatic entitlement is not available where a condition such as severe visual impairment or deaf blindness clearly merits the highest mobility rate and is not going to be reversed. Automatic entitlement would remove uncertainty and permit administrative streamlining in these cases.

30 November 2011

### Written evidence submitted by Scope

We welcome this opportunity to give evidence to this inquiry. We particularly welcome the chance to outline our concerns about the assessment process, and make clear our ideas about what needs to happen to ensure that the Personal Independence Payment is best designed to support disabled people can achieve their potential and lead the lives they value.

#### 1. About Scope

1.1 Scope is a leading disability charity that supports and works with disabled people and their families at every stage of their life. We believe disabled people should have the same opportunities as everyone else and we run campaigns with disabled people to make this happen. Scope operates in England and Wales and provides localised, individual care and support, residential, information and advice, employment and education services for disabled people and their families. As a charity with expertise in complex support needs and cerebral palsy we never set limits on potential.

#### 2. Summary

Scope is deeply concerned about the Government's plans to reform DLA and introduce PIP. We know that DLA provides invaluable support to many disabled families; without it, their ability to lead full and independent lives will be severely compromised. We agree that DLA is in need of reform, but believe that the draft initial assessment, as it currently stands, is not fit for purpose and will result in PIP being poorly targeted and many disabled families losing out on much-needed support. We know from our research that an assessment that focuses only on impact of impairment—and fails to take into account the practical, environmental and social barriers disabled people face—will produce an inaccurate reflection of the disability-related costs that they incur in their everyday lives. We urge that the Government reconsider the draft assessment criteria and look into alternatives that would provide better targeted support, and could reduce costs without impeding disabled people's capabilities.

#### 3. The need for DLA reform, including: how well understood DLA is; why the DLA caseload and expenditure has increased; the effectiveness of the decision-making and review process for DLA.

3.1 DLA is an invaluable source of support for disabled people who incur significant—often prohibitive—additional costs as a result of living with an impairment or condition. Increased disability-related living costs—on top of stark inequalities in educational and employment outcomes, as well as a lower wages than non-disabled people for the same work—mean disabled people are disproportionately likely to live in poverty.<sup>50</sup> The proportion of disabled households in poverty is far higher than that of non-disabled households (23.1% and 17.9% respectively). When additional disability costs are factored in, the proportion of disabled households in poverty rockets—from 23.1% to 47.4%.<sup>51</sup> Many of the disabled people in touch with Scope tell us that if their DLA was reduced or removed, they would be destitute. One respondent to a survey we commissioned in late 2010 of disabled people and parents of disabled children said: "If the government took DLA from me, or even reduced it, we would be on the poverty line and would very likely be homeless..."<sup>52</sup>

3.2 We believe DLA is in need of reform. The current assessment is overly complex: it is 55 pages long; many of the questions it asks requires the applicant to be able to comprehend multiple pieces of information (eg asking whether a claimant has difficulty getting out of bed because of motivational issues and how long it takes them to get up in the morning), which is problematic for applicants with learning disabilities. It is heavily centred on the physiological limitations arising from a person's impairment or condition—not on the social, practical and environmental barriers that produce the disability-related costs towards which DLA is aimed to contribute. And yet, research (attached with this submission) demonstrates that focusing on impairment or condition only produces an inaccurate picture of an individual's disability-related costs.<sup>53</sup>

3.3 The current assessment process is also built upon a "deficit model" of disability: focusing on what a claimant cannot do because of their impairment, rather than attempt to identify the barriers and costs that inhibit their ability to live a full and independent life.

3.4 As a charity with expertise in disability and complex needs, we know that for a great many disabled people DLA is a lifeline they need for paying for the additional support they need, as a result of barriers they

<sup>50</sup> National Equality Panel *An Anatomy of Economic Inequality in the UK—Summary* (CASE: London, 2010)

<sup>51</sup> Sen, A. *The Idea of Justice* (Allen Lane: 2009)

<sup>52</sup> Survey conducted by ComRes, commissioned by Scope, late 2010. Sample size: 845.

<sup>53</sup> Wood, C & Grant, E. *Counting the Cost* (London: Demos, 2010)

face while carrying out everyday activities that many non-disabled people may take for granted. The following quote, from a respondent to the aforementioned survey provides a useful example: “I use my DLA to pay for my ironing and buy gifts for my family who help with cooking and cleaning and doing tasks when I am too tired or my limbs are not fully functioning—usually at the end of the day having been at work all day!”<sup>54</sup>

3.5 We firmly believe that disabled people are best placed to decide how to spend their DLA to meet their needs. However, we remain concerned that basing the eligibility for PIP solely on impact of impairment—and not considering the wider social barriers, and extra costs connected to these, that disabled people face—will risk turning PIP into another health and social care budget. DLA occupies a unique position in the welfare system—as PIP will too—in that it is the only benefit designed to contribute towards the additional costs of disability. It is therefore imperative that the DWP understand the nature of the barriers disabled people face. We believe there is a great deal more work to be done on how these barriers and the additional costs connected to them can be reduced or removed by innovative policy reform and strategic investment.

3.6 There is a range of reasons as to why DLA caseload and expenditure has increased. As people live longer, so the proportion of DLA claimants over the age of 65 increases. Claudia Wood points out: “In 2002–03, the oldest DLA claimant would therefore be 75—but by 2010–11, they would have reached 84, whilst thousands of septuagenarian DLA claimants follow on behind.”<sup>55</sup> The prevalence of disability has increased, as research shows.<sup>56</sup> The number of adults reporting conditions, and apparent increases in autism and dementia should also be taken into account.<sup>57</sup> With such low rates of fraud, the increase in DLA caseload should not be seen negatively; rather, they demonstrate growing awareness and take up of vital support that is available to help disabled people lead the lives they value.<sup>58</sup>

3.7 We are concerned about the effectiveness of the decision-making around DLA claims. Statistics for 2009–2010 show the proportion of appeals that were upheld in the appellant’s favour was at 41%.<sup>59</sup> We believe that reforming the assessment process to make it more multidimensional and account for social, practical and environmental barriers would produce a more accurate reflection of the costs a disabled person faces, which, in turn, would lead to more effective decision-making and a lower rate of appeals.

#### 4. *The implications of a reduction in expenditure, including: the implications of focusing on those with the greatest needs; the likely impact of having only two rates of PIP in the “daily living” component; the number of current DLA recipients who would not be eligible for PIP*

4.1 Scope remains extremely concerned about the Government’s plans to reduce the DLA budget by 20%. That this target was set out long before the plans to introduce PIP were made public exacerbates concerns that this target is based on budgetary decisions—not on evidence of claimants’ needs or the barriers they face. We are very concerned that setting this savings target *prior* to the rollout of PIP will have a direct impact on the outcomes of the assessment process for this benefit—resulting in many disabled people not getting the level of support they need. We believe the Government should postpone plans to reduce spending by 20% until a clear, robust evidence base of need has been established.

4.2 We strongly believe that if DLA—and PIP—is to serve its purpose as a contribution towards the additional costs of living with a disability should target disabled people with the greatest disability-related costs and not those perceived to have the greatest impact of impairment. We believe the initial draft of the PIP assessment criteria—“with a strong focus on care and mobility” and “the impact of a health condition or impairment”—remains a highly medical test, formulated on a misguided interpretation of need.<sup>60</sup> We worry that any reduction in expenditure will make it more likely that disabled people who are assessed as having a low impact of impairment—but who have high disability-related costs—will miss out on much-needed support and could be pushed further towards the margins of our society.

#### 5. *Whether automatic entitlement should apply to people with some conditions or impairments and whether some people should receive awards for indefinite periods*

5.1 Scope does not believe that disabled people should be automatically entitled to DLA or PIP on the basis of their condition or impairment. This is because we believe that condition or impairment is not an appropriate “proxy” on which to determine eligibility. We know from our research, conducted by the independent think

<sup>54</sup> Respondent to survey carried out by ComRes, commissioned by Scope, in 2010. Sample size: 845.

<sup>55</sup> Wood, C. “Disability Stats: the devil in the DWP detail” Public Finance Opinion, 9 August 2011, <http://opinion.publicfinance.co.uk/2011/08/disability-stats-devil-in-the-dwp-detail/> (accessed August 2011)

<sup>56</sup> Berthoud, R. *Trends in the Employment of Disabled People in Britain* (Essex: Institute for Social and Economic Research, 2011)

<sup>57</sup> Papworth Trust, *The Key Facts About Disability: a review of the literature* (Cambridge: Papworth Trust, 2008); Brierley, C. “Study supports theory that rise in autism is related to changes in diagnosis” *Medical News*, 9 April 2008, <http://www.medicalnewstoday.com/articles/103315.php> (accessed February 2011); Association of Directors of Adult Social Services *Adult Social Care Submission* (London: ADASS, 2010)

<sup>58</sup> Fraud levels for DLA are—at 0.5%—extremely low; whereas, for other benefits like Jobseekers’ Allowance, they are significantly higher. Office for National Statistics *First Release: Fraud and Error in the Benefit System: Preliminary 2010–11 Estimates* (Leeds: DWP, 2011)

<sup>59</sup> Miller, M. “Disability Living Allowance: appeals” *Hansard*, 16 March 2011, <http://www.theyworkforyou.com/wrans/?id=2011-03-16a.45516.h> (accessed September 2011)

<sup>60</sup> DWP Personal Independence Payment: initial draft of assessment criteria—a technical note to support the initial draft of the assessment regulations (London: DWP, 2011)

tank Demos that social, practical and environmental factors—such as living in unsuitable housing, not being able to access public transport, being socially isolated—are key drivers of the additional disability costs a disabled person incurs, and it is according to these that eligibility for DLA or PIP should be assessed. Measuring the impact of a person’s impairment or condition alone will tell the assessor very little about the barriers and costs towards which DLA and PIP are supposed to contribute.

5.2 However, we recognise that the onset of some conditions—terminal illness for example—will mean that many disabled people will suddenly incur significant disability-related costs as they have to adapt to living with a newly acquired impairment. We believe it is paramount that these people receive the financial support they need during this time. Nonetheless, we believe that eligibility for this support should be based upon the barriers and costs a disabled person incurs *as a result of their impairment or condition*, and not on the basis on having that condition or impairment on its own.

## 6. *The implications of a six month qualifying period*

6.1 Scope is strongly opposed to plans to double the “Qualifying Period” (that is, the length of time for which a claimant has to have passed the eligibility criteria *prior* to making a claim) with that of Attendance Allowance (AA) and extend it from three to six months. This is likely to have negative implications for disabled people—particularly those with a newly acquired impairment or condition—who will then have to wait for a significantly longer period of time before they are able to access support. This is especially concerning given that the initial costs incurred from adapting to living with a disability—*ie* installing new adaptations in the home, *etc*—can place great pressure on the financial stability of a disabled person.

6.2 While we agree with the Government that some disabled people who incur disability costs early on will be able to access “an element of coverage” via other mechanisms like the NHS travel costs scheme or other social security benefits, we do not believe that these will—or should—cover the gap in need that will arise from extending the qualifying period.<sup>61</sup> Regarding the NHS Healthcare Travel Costs Scheme (HTCS), this has its own eligibility criteria, and so a disabled person who would be entitled to DLA, but not HTCS would not receive support. Also, the HTCS is designed only to help with travel costs from attending appointments as referred by their “GP, dentist or hospital consultant”.<sup>62</sup> Assuming a claimant *is* eligible for the HTCS in the first place, it is clear that any extra costs incurred from other activities—such as visiting family and friends, *etc*—that fall outside of this limited remit would not be covered. Regarding social security benefits, plans to extend the qualifying period have come at a time when the Government is radically reforming many of these alternative sources of support—like payments from the Social Fund. Extending the qualifying period effectively extends the time in which a disabled person will have to meet their disability costs themselves—a time that could wipe out any savings that they have, drive them deeper into debt and push them further towards poverty. For these reasons, Scope is against the proposal to end the qualifying period as we are certain it will have a negative impact on disabled people.

## 7. *The design of the PIP assessment, including: the assessment criteria and design; whether the assessment can objectively assess those with mental, intellectual and cognitive conditions and with fluctuating conditions; and the extent to which aids and appliances should be taken into account in the assessment*

7.1 We believe that any assessment that centres solely on impact of condition or impairment will lead to PIP being poorly targeted and many disabled people missing out on vital financial support.

7.2. We believe that the activities and descriptors around which the initial assessment criteria are centred upon are extremely limited in scope. For example, in the section relating to the Mobility Activities “Moving Around”, the descriptors focus on whether the applicant can move between 200 and 50 metres—with or without the use of a manual aid, a manual wheelchair or an assisted aid.<sup>63</sup> While these descriptors might capture information about the impact of an individual’s impairment or condition on their mobility, they will tell the assessor very little about the additional disability-related costs that a disabled individual incurs in order for them to get out and about and participate in social and cultural life. In a survey commissioned by Scope in late 2010, disabled people and parents of disabled children flagged the impact of extra costs incurred by, for example, needing to pay for expenses (extra seats, transport costs, *etc*) incurred by their carer when going on holiday or when going out to the cinema or theatre. Similarly, impairment-centred descriptors such as those mentioned above will fail to capture any information about whether a disabled person is unable to access public transport and so has to pay—often very high—fares for private hire taxis, so as to attend appointments, do their shopping, see their family and friends, volunteer in their community. In response to the survey, one disabled person noted: “I spend as much on taxis as the food I’ve bought therefore doubling each visit to the shops.” To take another example from the initial draft of assessment regulations—Dressing and Undressing (section 8 of the proposed Daily Living activities)—the proposed descriptors are designed to determine the extent to which an applicant may or may not need assistance when dressing and undressing. However, such questions will tell the assessor little about whether the disabled applicant incurs additional costs by having to pay for a carer in order to help them dress; whether they have to pay more for “specialist” items of clothing,

<sup>61</sup> DWP *Personal Independence Payment—Policy briefing note: Required period condition* (London: DWP, 2011)

<sup>62</sup> NHS “Healthcare Travel Costs Scheme” [nhs.uk](http://www.nhs.uk/nhs.uk/nhsengland/Healthcosts/pages/Travelcosts.aspx), 14 July 2011, <http://www.nhs.uk/nhsengland/Healthcosts/pages/Travelcosts.aspx> (accessed August 2011)

<sup>63</sup> DWP *Personal Independence Payment: initial draft of assessment regulations* (London: DWP, 2011)

which are often extremely expensive; whether they have difficulties getting out and about and so have to order their clothes online, and incur significant additional costs (which a non-disabled person would not have to incur) as a result. In response to the survey aforementioned, the mother of a disabled child pointed out: "The person referred to is only small in height so buying clothes to fit is difficult and costly." Another disabled respondent said: "Buying clothes—I can only buy mail order which is more expensive." Many disabled people incur significant additional costs due to having to repeatedly wash clothes due to incontinence; but, again, such extra disability costs will not be captured by the limited range of questions and descriptors set out in the current draft assessment criteria. We remain very concerned that many disabled people will continue to incur prohibitively high additional disability-related costs, which will not be flagged by the assessment in its current form. Ultimately, we believe that the initial draft criteria for the PIP assessment are not fit for purpose.

7.3 We therefore urge the Government to reconsider the initial draft criteria proposed for the PIP assessment, and to instead explore developing an alternative model that is much more multidimensional in scope. Over the course of this summer, Scope, along with other disability charities, has been undertaking a project to design and develop an alternative PIP assessment model. We have been liaising with representatives from academic institutions, think tanks, member organisations of the Association of Directors of Adult Social Services, and Disabled People's Organisations. We are in ongoing discussions with the DWP and the PIP Assessment Development Team, and are expecting to submit our paper, which will set out a blueprint for an alternative model, in the autumn of 2011.

#### 8 *The steps DWP needs to take to ensure that its reform proposals are clearly and effectively communicated to claimants and the general public*

8.1 Many of the disabled people we are in contact with, and who receive DLA express fear and anxiety over about will happen to them as a result of the reforms to DLA. It is therefore imperative that the DWP communicate these proposals sensitively and cautiously. We appreciate the level of engagement by the DWP with Scope and the rest of the sector thus far, but urge both the Government to take on board the concerns being voiced by disabled families, disability charities and disabled people's organisations, reconsider the draft assessment criteria and seriously look into an alternative model that would provide more targeted support and would reduce costs without risking disabled people's independence.

We thank the Committee for the opportunity to respond to this inquiry and would welcome the opportunity to further discuss the ideas presented in this paper at an oral evidence session.

2 September 2011

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### Written evidence submitted by the National Autistic Society (NAS)

#### ABOUT THE NAS

The National Autistic Society is the UK's leading charity for people affected by autism. We have 20,000 members, 100 branches and provide a wide range of advice, information, support and specialist services to 100,000 people each year including a welfare rights helpline and Prospects, the NAS' specialist employment service for people with autism. A local charity with a national presence, we campaign and lobby for lasting positive change for people affected by autism.

#### OVERVIEW

1. Since the Government announced that £1 billion is to be cut from the projected spend on Disability Living Allowance (DLA) over the next three years and that DLA would be replaced by a new benefit Personal Independence Payment (PIP), the NAS has been inundated with emails and calls from people with autism<sup>64</sup> and their families worried about the proposed changes.

2. In response to this we carried out some qualitative research on what people use their DLA for and the impact that losing the benefit could have. This resulted in the publication of our *Who Benefits?* report,<sup>65</sup> which outlines the central importance of DLA for people with autism and shows that for many it is an absolute lifeline. *Who Benefits?* helped us to, among other things, formulate our response to the Government's initial consultation on the DLA reforms.

3. On 10 March, in response to a written question,<sup>66</sup> Minister for Disabled People, Maria Miller MP said that the Government agreed with many of the points raised in *Who Benefits?*, and were looking closely at how these recommendations can be incorporated into the design of the assessment.

4. *We are not opposed in principle to the review of DLA* as it has not always worked as well as it should for people with autism. We commonly hear of people with autism and their families having to battle to access

<sup>64</sup> The term autism is used throughout this document to refer to all people on the autism spectrum including Kanner autism, Asperger Syndrome and high-functioning autism.

<sup>65</sup> James, L (2011), *Who Benefits?* London: National Autistic Society

<sup>66</sup> <http://www.publications.parliament.uk/pa/cm201011/cmhansrd/cm110310/text/110310w0003.htm#11031072001181>

DLA. In particular, the current application system tends to focus too much on physical disabilities. Therefore, reform to DLA has the potential to ensure that the award better reflects the true needs of people with autism.

5. However, we have very significant concerns about the way the Government has proposed to replace DLA with the new benefit. We therefore welcome the Work and Pensions Select Committee's inquiry into the reform and would also welcome the opportunity to give oral evidence to the Committee, if requested.

6. Below, we set out our position on the key areas covered by the Select Committee as laid out in its terms of reference.

#### ABOUT AUTISM

7. Autism is a lifelong developmental disability that affects how a person communicates with, and relates to, other people. It also affects how they make sense of the world around them. It is a spectrum condition, which means that, while all people with autism share certain difficulties, their condition will affect them in different ways. Some people with autism are able to live relatively independent lives but others may need a lifetime of specialist support. People with autism may also experience over- or under-sensitivity to sounds, touch, tastes, smells, light or colours.

8. Asperger syndrome is a form of autism. People with Asperger syndrome are often of average or above average intelligence. They have fewer problems with speech but may still have difficulties with understanding and processing language.

9. Research has shown that 1 in 100 children has autism and recent figures from the NHS Information Centre have confirmed a similar prevalence figure among adults.<sup>67</sup> By applying the one in 100 figure we estimate that there are approximately 350,000 working age adults with autism in the UK, of whom just 15% are in full-time employment.<sup>68</sup>

#### *The implications of a reduction in expenditure, including: the implications of focusing on those with the greatest needs*

10. DLA is a key benefit for people with autism to help them meet the additional costs that arise as a result of their disability. People with autism are some of the most vulnerable in society, routinely struggling to access the services they need. Consequently outcomes are poor, indicated by our research:<sup>69</sup>

- Over 60% of adults with autism rely on their families for financial support and 40% live at home with their parents.
- 63% of adults with autism report that they do not have enough support to meet their needs.
- As a result of this lack of support, a third of adults with autism have developed a serious mental health problem.
- Just 15% of adults with autism are in full time employment.

11. We surveyed how people with autism use their DLA as part of our latest campaign *Who Benefits?* Hundreds of people responded to our survey telling us that they were reliant on it to travel independently, access community services and get the support they need to manage their day to day lives. Without it, people told us they would be more socially isolated and would be much more likely to have poorer mental health.

12. The Government have said that they want to focus on those with “greatest need”, but have yet to fully explain what they mean by this. Looking at the draft criteria for the benefit, it appears that the Government are replicating the social care system in defining greatest need rather than looking holistically at the individual, the barriers they face in gaining/maintaining independence and the costs incurred as a result of their disability.

13. We are very worried that those who have considerable extra costs because of their disability, but have what is perceived as lower needs in relation to care and support will lose out as a result of these reforms.

14. A 2009 National Audit Office (NAO) report<sup>70</sup> demonstrated the huge savings that could be made in the medium-to long-term by ensuring that the needs of adults with autism were met. The report focused in particular on adults with Asperger syndrome and high functioning autism—whose needs are often least obvious. It found that identifying these individuals and supporting them could save over £67 million a year depending on how many people were identified. Much of the support that would help ensure these savings would be low level support, such as travel training, outreach and social skills training. Ever tightening social care eligibility criteria

<sup>67</sup> Brugha, T *et al* (2009) Autism Spectrum Disorders in adults living in households throughout England: Report from the Adult Psychiatric Morbidity Survey 2007 London: The NHS Information Centre for Health and Social Care.

<sup>68</sup> Baird G, *et al* (2006). Prevalence of disorders of the autism spectrum in a population cohort of children in South Thames: the Special Needs and Autism Project (SNAP). *Lancet*, 368, 210–215.

Reid, B. (2006) Moving on up? Negotiating the transition to adulthood for young people with autism. London: NAS.

<sup>69</sup> In 2007, we surveyed over 1,400 adults with autism and parents about their experiences of living with autism as an adult. The findings are presented in our *I Exist* report. See: <http://www.autism.org.uk/~media/NAS/Documents/About-autism/Autism-library/Magazines-articles-and-reports/Reports/Our-reports/1%20Exist%20-%20the%20message%20from%20adults%20with%20autism.ashx>

<sup>70</sup> National Audit Office (2009), *Supporting People with Autism Through Adulthood*. London: NAO

makes it increasingly unlikely that a significant number of people with autism can access this type of support through social care. We know that some people with autism are using their DLA to fund this type of support, potentially saving significant funds to the public purse.

*The design of the PIP assessment, including: the assessment criteria and design; whether the assessment can objectively assess those with mental, intellectual and cognitive conditions and with fluctuating conditions*

#### Assessment criteria

15. It is vital that any descriptors used to determine eligibility must be developed to take into account the difficulties people with autism have as a result of their disability. This must include difficulties with social communication, imagination, interacting with other people and sensory sensitivities. Experience with the Work Capability Assessment (WCA) for Employment and Support Allowance (ESA) has shown us that descriptors can be by their very nature be very narrow and their use removes the ability to take a broad and holistic look at a person's extra needs. If they are to be used, then great care must be taken to ensure that they are fair and fit for purpose.

16. We were pleased when the Government in statements and documents placed emphasis on criteria such as communication and ability to plan a journey. We had also stressed the importance of involving people with autism and their families in the development of the assessment, and felt that DWP's request to help them find 60+ people with autism who would be interested in helping test the draft criteria was a positive development. We are currently gathering feedback from some of the volunteers with autism who took part in the testing of the draft criteria and we would be happy to share this with the Committee.

17. However we have deep concerns about the draft criteria and descriptors which were published in May. Our full response to the DWP<sup>71</sup> covers all NAS' concerns, but below is an outline of our main concerns.

#### Draft assessment criteria

18. The criteria and their attendant descriptors, despite emphasis from the Government on issues of independence and participation and society, seem to mainly focus on the bare minimum needed to survive. The Government has said that "Personal Independence Payment will consider the impact an individual's impairment or health condition has on their daily life". Yet, the criteria appear to focus on care and support needs.

19. Moreover, despite the Government's stated adherence to the social model rather than the medical model of disability, the criteria and descriptors focus on the physical. For instance, a person only gains points in various scenarios if they require continual or intermittent assistance—defined as physical intervention.

20. Ideally the definition of assistance in the draft regulations needs changing to include non physical intervention, and should be interpreted broadly to cover supervision, as well as direct physical assistance. The general lack of reference to supervision throughout the regulations also represents a massive gap regarding something vital to ensuring that some people with disabilities are safe. As well as ensuring an individual's safety, supervision is also needed by some people with a disability to support the development of more independence.

21. *Communication and planning a journey* are extremely important with respect to the autism spectrum, and while we welcome their inclusion in the criteria, we have concerns about how they are currently drafted.

22. On communication, we believe that the descriptors over simplify what it means to be able to communicate, but at the same time conflate the ability to communicate with the ability to make a decision and make that known. Communication covers so many aspects: being able to speak to another person face to face; making oneself understood; and understanding the nuances of language, tone of voice *etc*, and responding appropriately. These different levels of and barriers to communication are not reflected adequately in the descriptors.

23. Communication support for individuals with autism may be provided by a family member or a friend as opposed to a trained professional. It is unclear from the descriptors or the guidance whether and how this type of communication support would be taken into account and whether an individual could qualify for PIP as a result. The technical notes refer to whether an individual needs communication support as meaning assistance from a "trained person". It is important to recognise that the fact that an individual with autism can, with the help of a carer or family member, communicate with someone unknown to them does not mean they do not have a disability. Indeed the requirement to have this helper present at all times incurs higher costs, for which PIP/DLA is supposed to compensate.

24. We are also concerned about how suitable an interview environment is for a professional to properly and accurately assess an individual's communication difficulties. For example, if an individual on the autism spectrum has known about their interview for a number of weeks they may spend those weeks "practising" what to say and how to say in order to come across well—in a way that will not truly reflect their actual

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<sup>71</sup> Information provided, not printed.



communication struggles. Therefore, they may come across as not having any noticeable communication difficulties and be wrongly assessed.

25. An effective diagnostic assessment to assess someone's communication skills would often be carried out over period often of several hours across different days and in different environments. This demonstrates the real challenges of the current approach to the assessment in ensuring accuracy and fairness; if an autism expert needs a significant amount of time to fully assess communication skills, it would be a big ask to expect a generalist assessor to be able to accurately assess the communication needs of someone with autism in a short interview.

26. With regard to *planning and following a journey*, the descriptors are not useful in trying to describe the myriad of problems people with autism face with regard to travel. It is not clear for example whether they would cover people who find it difficult to use public transport due to sensory hyposensitivity; or how they would accommodate a person with autism who, after many "walk throughs" can execute a familiar journey, but who would suffer great distress and be unable to complete the journey if were affected by delays or detours.

27. We also have concerns that none of the descriptors appear to sufficiently take into consideration individuals, who are able to undertake tasks but require supervision in order to carry out the tasks safely.

28. Moreover, no criterion takes into account or covers challenging behaviour, self-neglect or self-harm. For example, one mother told us of her needing to watch over her son all night in order to make sure he doesn't get up in the middle of the night to try and cut himself, as he is obsessed with knives. This is a great responsibility for her, and would also make holding down a job very difficult for her, meaning a severely reduced income—yet we are not clear where this would be covered by the current draft criteria.

*The assessment process, including: lessons to be learned from the Harrington review; whether automatic entitlement for some is desirable; and delivery of the PIP assessment*

29. We have specific concerns about the introduction of a face to face assessment for the new benefit, particularly given our experiences of the WCA, which includes a face-to-face assessment with a medical professional.

30. NAS followed a group of people with autism through the WCA process and identified that the medical assessment was a particular barrier to having needs fully assessed, particularly as many reported that the Atos doctors undertaking the assessment did not have a full understanding of the needs of people with autism. This is unsurprising given the low awareness and understanding of autism across health, social care, education, employment and benefits. Research carried out by the NAO in 2009 found that 80% of GPs felt that they needed more training to help people with autism. The example below shows how easily a face to face assessment with a professional that does not understand autism can lead to that individual being unfairly assessed.

ANNE

Anne is in her early 20s and was recently diagnosed with Asperger syndrome. Keen to get the support she needs to find work, Anne recently applied for Employment and Support Allowance. Three days after getting a formal diagnosis of Asperger syndrome Anne went for her medical assessment. The doctor carrying out the assessment rushed through the appointment in just 15 minutes, asking nothing about Anne's Asperger syndrome and ignoring a seven page psychiatrist's report about her diagnosis. The doctor then recorded that he saw "no evidence of communication difficulties" in his report to the ESA decision maker, despite communication difficulties being fundamental to a diagnosis of Asperger syndrome. Six days later, Anne's application for ESA was rejected. She later found out that she had been scored zero points on her medical assessment. It was only after going to a tribunal that Anne was finally awarded the benefit to which she was entitled.

31. The case study demonstrates the importance of ensuring that any decision around the allocation of a benefit takes into account any expert assessment of an individual. We would not expect every medical professional to have a specialist understanding of autism, so where expert reports are available, they must be used. Expert reports will be much more comprehensive than any assessment made by a benefits assessor is ever likely to be. In instances, where a detailed report of need, carried out by a specialist is available, we would question the value of a face to face assessment with someone who does not have this expertise. The face to face assessment will add unnecessary anxiety to the individual, who has probably already been subject to numerous assessments and tests. It also makes the process more costly at a time where finances are increasingly tight.

32. *We therefore recommend a tiered approach to the PIP assessment process.* A paper based assessment, including a self assessment and expert reports would constitute a first "tier" to the assessment process. If a person's needs can be demonstrated without them having to attend a face to face assessment, then carrying these out as a matter of routine will be an unnecessary expense. If need has not been sufficiently demonstrated through this process, it would be at this point that a face to face assessment could be introduced. We also believe that a paper based assessment should be sufficient for those who currently qualify for higher rate mobility as a result of a "severe mental impairment".

33. Lord Freud recently stated during a Lords' debate that where it is: "not realistic, helpful or appropriate", the Government would not insist that applicants for PIP be seen face to face. We would welcome further

clarification of what this means and safeguards on the face of the Bill to ensure that individuals are not put through a face to face assessment, if inappropriate.

34. We have also been emphasising to government how crucial the role of a supporter / advocate is for people with autism, if they do have to undergo a face to face assessment. The Government has accepted our recommendations and given assurances that the role of advocate will be strongly supported.

35. Our concern in this area is that we have heard of supporters/carers who have been ignored when trying to support individuals through the WCA, so further reassurances about their role in this process would be welcome.

#### Delivery of the assessment

36. The difficulties of the face to face assessment part of the WCA are not confined to autism and the recent review of the WCA, carried out by Professor Malcolm Harrington, recognised this. Professor Harrington recommended that there needed to be “mental, intellectual and cognitive” champions in each “medical assessment centre” to support professionals in assessing those with “mental, intellectual and cognitive disabilities” for ESA. We support this recommendation if it means that there will be professional with expertise in autism in each medical centre.

37. We also believe that professionals involved in any future face to face assessments for PIP will need access to this type of expertise too.

38. As well as accessing more expert support, any assessor will also need training in autism to recognise support needs in less complex cases and to be able to know when to ask for more expert support in more complex cases.

39. On a final note, in relation to training, we would like to make it clear that any training given to assessors must be robust and teach assessors how to recognise and assess someone on the spectrum. In the past, NAS has been mentioned in Parliament in the context of having supplied autism training to Atos, when in fact this “training” consisted of a one hour presentation at a conference comprising a basic introduction to autism.

#### *The extent to which PIP will act as a gateway to other benefits, including Carers Allowance and the Motability Scheme*

40. DLA is not only an important benefit in its own right but is also an important gateway to other benefits and Carer’s Allowance in particular.

41. We carried out a survey of carers in 2009. Over 300 carers responded to our survey and a staggering 83% of respondents were caring for someone with autism for over 50 hours a week, which among other things had a significant impact on their ability to work. Only just over half of respondents were in receipt of Carer’s Allowance, suggesting that already there are challenges to accessing the benefit. If the change to PIP means that fewer people will receive the benefit, this will make it harder for carers to claim Carer’s Allowance, but will not change the needs of those with autism who are being cared for. We urge the DWP to look carefully at criteria for Carer’s Allowance to ensure individuals are not being doubly disadvantaged by the change.

42. Concessionary travel, such as a blue badge or concessionary travel passes are another benefit that many people with autism find invaluable. Whilst local authorities must not use DLA or PIP as the only proxy for access to such benefits, leadership from Government will help ensure that people with autism can continue to access blue badge or concessionary travel passes even where they are no longer eligible for PIP/DLA.

43. Entitlement to DLA is also important as it passports to higher amounts of ESA, Income Support, JSA, Housing Benefit, Council Tax Benefit, Working Tax Credit and Child Tax Credit.

“DLA mobility is a gateway benefit that was required to obtain a concessionary bus pass, reducing the expense of travel because my sensory issues prevent me driving ... I do voluntary work for the Citizens Advice Bureau which wouldn’t be possible without DLA mobility because of the bus pass.”

*Adult with Asperger syndrome*

#### *How DLA/PIP should apply to children and people over the state pension age*

44. We welcome the current direction from Government that children’s DLA is not going to be reformed. As a DWP research paper<sup>72</sup> from last year found, there are significant differences between the needs and experiences of adult benefit recipients, and parents of child recipients of DLA.

45. We believe that, if the Government plans in the future to extend PIP to children as well as to those over the state pension age, then a separate consultation exercise should be undertaken, which deals with the specific issues relating to these age groups, and learns lessons from the implementation of PIP as evidenced through the independent reviews that are stipulated on the face of the Bill.

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<sup>72</sup> DWP Report 649: The impact of Disability Living Allowance and Attendance Allowance: by Anne Corden, Roy Sainsbury, Annie Irvine and Sue Clarke

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*The steps DWP needs to take to ensure that its reform proposals are clearly and effectively communicated to claimants and the general public*

46. The print media has over recent months run many stories about “scroungers” or the “work-shy”. As well as containing either huge generalisations, or unusual anecdotes, these stories often conflate DLA and work related benefits, wilfully or otherwise. “Disability benefit” has become a hashed, pejorative term for money received by people who can work, but don’t.

47. Obviously Government cannot control how the media reports issues, but care must be taken with regard to timing of press releases, and statistics contained therein.

48. The backdrop of the 20% cut in DLA spend (announced before the details of the DLA reform were announced); and the fact that the DLA reform consultation period closed after the Welfare Reform Bill was published, have not helped to dispel fears that this is a cost-cutting exercise, and that the Government is not really listening to some of the most vulnerable and isolated people in this country.

2 September 2011

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### Supplementary evidence submitted by the National Autistic Society

#### 1. About autism<sup>73</sup>

Autism is a lifelong developmental disability that affects how a person communicates with, and relates to, other people. It also affects how they make sense of the world around them. It is a spectrum condition, which means that, while all people with autism share certain difficulties, their condition will affect them in different ways. Some people with autism are able to live relatively independent lives but others may have accompanying learning disabilities and need a lifetime of specialist support. People with autism may also experience over- or under-sensitivity to sounds, touch, tastes, smells, light or colours.

Asperger syndrome is a form of autism. People with Asperger syndrome are often of average or above average intelligence. They have fewer problems with speech but may still have difficulties with understanding and processing language.

Research has shown that 1 in 100 children has autism and figures from the NHS Information Centre have confirmed a similar prevalence figure among adults.<sup>74</sup> By applying the 1 in 100 figure we estimate that there are approximately 350,000 working age adults with autism in the UK, of whom an NAS survey suggests that just 15% are in full-time employment.<sup>75</sup>

#### 2. Introduction

On 23 November, NAS External Affairs Director Amanda Batten gave oral evidence to the Work and Pensions Select Committee about the impact on people with autism of the proposed reforms to replace Disability Living Allowance (DLA) with Personal Independence Payment (PIP).

At that meeting, Chair of the Select Committee Dame Anne Begg MP asked for a comparison of the first and second sets of the Personal Independence Payment (PIP) descriptors, which we have included below. We also did not get as much opportunity as we would have liked to discuss the delivery and process of the new PIP benefit, so we have included points on this topic here.

#### 3. PIP Descriptors

There have been a number of positive changes to the PIP descriptors between the first and second drafts of the criteria. Following our submission to DWP and discussions with officials we particularly welcome:

- The addition of the “Engaging Socially” descriptor: the first draft did not include any descriptors which recognised difficulties around social communication and interaction, which are the main barrier that people with autism face in trying to live an independent life. This new descriptor gives a better opportunity to assess people with autism more accurately
- Addition of “Making Financial Decisions” descriptor. This will help to begin to identify the difficulties many people with autism have around planning activities and thinking ahead

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<sup>73</sup> The term autism is used throughout this document to refer to all people on the autism spectrum including Kanner autism, Asperger Syndrome and high-functioning autism.

<sup>74</sup> Brugha, T et al (2009) Autism Spectrum Disorders in adults living in households throughout England: Report from the Adult Psychiatric Morbidity Survey 2007 London: The NHS Information Centre for Health and Social Care.

<sup>75</sup> Based on a working age population of approximately 37 million people and a prevalence rate of 1 in 100. Baird G, et al. (2006) Prevalence of disorders of the autism spectrum in a population cohort of children in South Thames: the Special Needs and Autism Project (SNAP). *Lancet*, 368, 210–215. Reid, B. (2006) *Moving on up? Negotiating the transition to adulthood for young people with autism*. London: NAS.

- Addition to definition of “communication support” of “support from someone experienced in communicating with the claimant”. The change to this definition is extremely welcome as it previously only referred to aids, adaptations or people “trained in communication support”. This did not take into account that the majority of people on the autism spectrum receive communication support from parents, family members or close friends.
- The scores within the “Planning and following a journey” descriptor are high enough to reflect the impact that people with autism have in this area
- The addition of a criteria around “supervision” within nearly all of the descriptors is helpful as many people on the autism spectrum are able to carry out certain activities but only whilst being supervised by someone. The addition of this term will help to better identify the kind of support many people with autism require, however it is problematic that supervision has been described as having to include the “*continuous* presence of another person”.

While we welcome the changes outlined above, *it has been difficult for us to assess the impact of the new criteria because although the second draft has scores attached to different categories within each descriptor, there are no accompanying thresholds outlining what scores are needed to qualify for PIP.*

We also have outstanding concerns about the second draft criteria and believe that if the assessment is to be fair and accurate for people with autism the following issues need to be addressed:

- We are concerned that some people with autism may only score low points across the majority of descriptors and that this may not give them enough of an overall score to qualify for either rate of PIP
- The first six of the nine Daily Living descriptors still focus heavily on the physical act of completing a task, and do not provide enough scope for taking account of the difficulties people with autism have in these areas. Although the inclusion of terms such as “prompting” and “supervision” are very useful when applied to the “act” of taking nutrition (for example), there are many people with autism who are not likely to need support with the actual act of eating but with things such as overeating or knowing *what* foods to eat or buy. The descriptors do not allow for capturing these types of difficulties and will make it hard for many people with autism to score any points in them.
- We believe that there needs to be a descriptor which adequately assesses peoples’ difficulties to manage their home and general health/hygiene—ie. People with autism or mental health problems may not know when to clean up their home or know when to wash their clothes, understand when their clothes are dirty or know when to vacuum or to clean the home.
- Within the “socially engaging” descriptor we have a concern that many claimants may have more severe difficulties than are captured in subsection (c) “needs social support to engage socially” but fall short of qualifying for subsection (d) which includes “overwhelming psychological distress...”. Many have regular, sustained anxiety in all social situations, rather than irregular bouts of extreme anxiety. *We believe this must be revisited, to ensure those with significant difficulty engaging socially receive the support they need.*
- We are particularly concerned that claimants will only have seven days between receiving notification of the assessment and the assessment itself. Communication difficulties associated with autism mean that many claimants may need longer than this to understand, perhaps with the assistance of a family member or carer, the meaning of the information they have been sent. Many people with autism also find changes in routine cause extreme anxiety, meaning that they may need time to plan a transportation route to the assessment location and come to terms with what the day will consist of. *We hope the Government will work with charities such as the NAS to ensure the system is fair for claimants with autism.*

#### *Key questions to raise with the Minister*

- *If a claimant who scores low points across many descriptors or scores medium points in very few descriptors will they still meet the threshold for any rate of PIP?; and*
- *Will the minister consider extending the seven day notification period for attending an assessment as this seems very short notice for people with disabilities to make arrangements to attend within only one week?*

#### *4. The process for Personal Independence Payment and the NAS’ key concerns*

At The National Autistic Society, one of our central concerns about the change from DLA to PIP is the delivery of the assessment. During the oral evidence session, we did not get as much opportunity to air our concerns in this area as we would have liked. Below we set out our preferred approach to the delivery of the assessment.

As we said in our initial written submission to the committee, we recommend a tiered approach to the assessment. This means that the claimant would fill in an application form initially with which they can submit evidence such as medical assessments or reports from clinical psychologists or their social worker who has

already assessed the person and knows them and how their autism affects them. They would only be called to an assessment if this evidence is not sufficient to demonstrate need.

An assessment by someone who is not a specialist in autism is unlikely to be as detailed or accurate as existing ones carried out by professionals who have knowledge or expertise of autism and know the claimant. Moreover, using existing assessments undertaken by healthcare professionals who know the claimant will save unnecessary costs of conducting another assessment by someone who is not an expert in autism.

Over the summer of 2011, the Department for Work and Pensions carried out testing of the PIP draft criteria on people from various disability groups who were already in receipt of DLA. Assessors met claimants in their homes and carried out mock PIP assessments using the initial PIP criteria to analyse the effectiveness of the 11 different descriptors which comprise the PIP criteria. Many of the volunteers who undertook mock assessments told us that they found it hard to give accurate answers verbally. They often had high anxiety levels and issues around having time to process the questions which made them feel they did not give accurate answers.

*Lord Freud said at Lords committee stage of the Welfare Reform Bill that the government agreed that there should be a tiered assessment for PIP as recommended by the NAS—we would like more details from DWP about how this would work in practise.*

**CASE STUDY:** One adult with Asperger syndrome who attended the mock PIP assessment told us that she could not think or react fast enough during the assessment and that she needed time to reflect in order to answer questions fully. She commented that: “oral assessments with people with autism are dangerous” due to high anxiety levels, needing longer to comprehend the meaning of a question and to think of all the relevant things to say in response. She added that high anxiety levels and an unfamiliar environment can add to the person being further impaired in their ability to communicate. She and many other volunteers who went through the PIP testing said that they felt they needed to be sent the questions on paper first to properly process them and give accurate answers once they had sufficient time to think about their difficulties in each area.

It is important to learn lessons from the Work Capability Assessment (WCA) for Employment and Support Allowance (ESA)—the NAS “Don’t Write Me Off” campaign followed several people with autism through the process of applying for ESA and going through the Work Capability Assessment.

We had many reports of people with autism attending the Work Capability Assessment for ESA where they had taken a parent/carer/friend along as support and that person being told by the assessor that they could not participate in the assessment, for example by clarifying the meaning of a question.

We believe that it is imperative that people with autism are able to take a support person to the assessment and that this person is allowed to “translate” questions for them so they can fully understand them. The support person should be allowed to give information about the claimant’s difficulties as people with autism often do not have insight into their own difficulties and people who know them best are frequently in a better position to explain their difficulties

*Lord Freud said at committee stage that the government agree that people must be allowed to take a support person to the assessment and that this person will be allowed to participate in the assessment—even answering on the claimant’s behalf where they are unable to do so*

**CASE STUDY:** A 20-year-old man with Asperger syndrome was filling in his DLA form with his support worker. She read out a question asking whether or not he could travel independently. He immediately answered “yes” even though his support worker had recently spent 6 weeks travel training him to learn a simple bus route to the local shops. This was the only journey he had ever learnt to carry out independently—if he was asked to carry out a different journey he would not be able to and would need the same support from his support worker for each new journey. However, because of his Asperger syndrome he took the question to apply literally, and only to his most recent experiences which were that he could now travel on one route independently. Due to his lack of social imagination he did not understand the wider meaning of the question, ie. That he had needed a lot of support to learn the one route he knew. This demonstrates how crucial it is that many people with autism have a support person with them during the assessment.

Key Questions to raise with the Minister:

- *Can the Minister make a commitment to further testing and trialling of the PIP criteria and assessment process with people who currently claim DLA to ensure that the process is fair to people with autism?; and*
- *Can the Minister indicate what type and amount of evidence will be sufficient for a decision to be made about whether someone is eligible for PIP without them needing to attend a further face to face assessment?*

**Written evidence submitted by Professor Steve Fothergill, Centre for Regional Economic and Social Research, Sheffield Hallam University**

SUMMARY

*The merits of the proposal to replace Disability Living Allowance (DLA) by Personal Independence Payment (PIP) can really only be assessed in the context of the role that DLA currently plays within the wider benefits system. What the evidence shows is that, for working-age claimants, DLA functions mostly as a top-up to Incapacity Benefit (IB). The rising numbers claiming DLA, and their distribution across the country, are therefore intimately linked to the factors underpinning IB claims more generally. The introduction of PIP will hit non-employed benefit claimants hardest, including many whose IB payments are also being squeezed.*

BASIS OF THE SUBMISSION

The present submission draws principally on the findings of a Sheffield Hallam University report, commissioned by the Department of Work and Pensions and published by the Department in 2009, looking at the characteristics and aspirations of the DLA recipients who also claim Incapacity Benefit (IB).<sup>76</sup> This is by some distance the largest group of working-age DLA claimants and, as far as the research team is aware, the study remains the most comprehensive assessment of this group that is currently available. The study included evidence from face-to-face interviews with more than 1,700 DLA claimants.

The figures in the report showed that in, February 2008, 1.25 million of the grand total of 1.7 million working-age DLA recipients also claimed IB or Severe Disablement Allowance (SDA). Employment and Support Allowance (ESA) is now being gradually introduced to replace IB, but it is unlikely that the preponderance of IB/SDA/ESA claimants among the working-age DLA claimant group will have changed much in more recent figures.

Furthermore, many of the remaining working-age DLA claims will be claims carried over into employment from periods on IB—a point supported by evidence in the Sheffield Hallam University report. And in addition, given that new claims to DLA can only be made by those *under* pension age, most of the DLA claims by men and women *over* state pension age are likely to be claims carried forward from pre-pension age IB claims.

The point here is that DLA claims are closely intertwined with wider incapacity benefit claims. An appreciation of this linkage is central to understanding why DLA claimant numbers have risen so much over the years and to assessing the likely impact of the introduction of Personal Independence Payments.

THE ROLE OF DLA

The Sheffield Hallam University research found that for non-employed working-age claimants, DLA functions primarily as a top-up to IB. The key pieces of evidence in this regard are the concentration of DLA claimants in exactly the same places as the wider stock of incapacity claimants, and the fact that in many respects DLA claimants are actually not very different from the wider group of non-employed incapacity claimants of which they form part.

Taking the issue of geography first, what has often been overlooked is that DLA claimants are very unevenly spread around the country. Table 1 illustrates this point by showing the districts<sup>77</sup> with the highest and lowest shares of the working age population claiming DLA with IB. The older industrial areas of the North, Scotland and Wales dominate the list of areas with the highest claimant rates, just as they dominate the list of areas with the highest overall IB claimant rates. By contrast, the claimant rate (for DLA and for IB) is far lower in much of southern England.

Turning to the evidence on the nature of the claimants, the Sheffield Hallam University report points to considerable similarities between working-age DLA claimants and other IB claimants:

- Both groups tend to be very poorly qualified.
- Both groups are dominated by manual workers, especially those from lower-grade occupations.
- Many in both groups have a track-record of substantial, continuous employment.
- Illness, injury or disability was easily the most important trigger of job losses for both DLA claimants and non-claimants.
- Labour market detachment is formidable in both groups.
- In terms of household type (partner, children, housing tenure *etc*) the two groups are almost identical.

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<sup>76</sup> C Beatty, S Fothergill and D Platts-Fowler (2009). *DLA claimants: a new assessment*, research report no 585, Department of Work and Pensions, London.

<sup>77</sup> Pre-2009 local authority districts

**Table 1**

DISTRICTS WITH THE HIGHEST AND LOWEST “DLA WITH IB/SDA” CLAIMANT RATES,  
FEBRUARY 2008

		<i>% of working age population</i>
<b>Top 20 Districts</b>		
1.	Merthyr Tydfil	8.5
2.	Neath Port Talbot	7.8
3.	Blaenau Gwent	7.3
4.	Easington	7.0
5.	Caerphilly	6.9
6.	Knowsley	6.9
7.	Glasgow	6.7
8.	Liverpool	6.7
9.	Blackpool	6.4
10.	Rhondda Cynon Taff	6.4
11.	Bridgend	6.3
12.	Inverclyde	6.2
13.	W Dunbartonshire	6.2
14.	Barrow in Furness	6.2
15.	Torfaen	6.0
16.	Carmarthenshire	5.9
17.	Bolsover	5.9
18.	Dundee	5.8
19.	Swansea	5.8
20.	Halton	5.8
<b>Bottom 10 Districts</b>		
397.	Runnymede	1.4
398.	Uttlesford	1.4
399.	S Northamptonshire	1.4
400.	Kingston-upon-Thames	1.4
401.	S Buckinghamshire	1.3
402.	Windsor and Maidenhead	1.3
403.	Elmbridge	1.2
404.	Surrey Heath	1.2
405.	Wokingham	1.2
406.	Hart	1.0

*Source:* ONS

What these points tell us is that DLA claimants and other IB claimants come from the same segment of the labour market and, essentially, from the same segment of society more generally. They have more in common with each other, as IB claimants, than with many other groups in the workforce.

On the other hand, there are also some points of divergence:

- DLA claimants are on average a little older.
- DLA claimants are likely to have been on incapacity benefits for longer.
- DLA claimants are less likely to have moved onto IB via a spell on unemployment benefits.
- DLA claimants are a little more likely to cite ill health, injury or disability as the principal cause of job loss.
- DLA claimants are affected by a somewhat different set of medical problems—often more clear-cut physiological issues.
- More DLA claimants say they “can’t do any work” and they tend to be more pessimistic about the trajectory of their health problems or disabilities.
- And DLA claimants are less likely to express an interest in returning to work.

These points tell us that there are some real differences between DLA claimants and other IB claimants, centred around health and disability. DLA claimants appear to face somewhat greater physical or mental obstacles to working than other IB claimants. This is hardly surprising, perhaps, since DLA requires care or mobility needs that are not necessarily implied by IB eligibility. Yet even these differences in health or disability rarely appear large. For instance, only a minority of DLA claimants say they can't do any work.

The overall impression, nevertheless, is that the differences between the two groups are ones of degree. The distinction between DLA claimants and other IB claimants is blurred at best. DLA functions primarily as a top-up for a sub-set of Incapacity Benefit claimants and in doing so it allows these claimants to live a little more comfortably on benefit than would otherwise be the case, and to do so for longer periods.

That DLA functions as a top-up for a substantial proportion of IB claimants could be regarded as no bad thing. Incapacity Benefit is not especially generous; DLA makes it more tolerable. In many cases this will be because, as originally intended, DLA offsets some of the financial costs of illness or disability. More to the point, Incapacity Benefit has become the principal means of long-term support for many of the most disadvantaged working-age adults—sickness or disability, poor qualifications and advancing years often disadvantage the same individual—especially in the parts of the country where over the last 20 or 30 years there have never been quite enough jobs to go around. The IB claimants with the most acute health problems or disabilities are among the most disadvantaged of all, and it is this group that accesses DLA.

#### *So why have DLA numbers risen so much?*

If we accept that working-age DLA claims are intimately bound up with IB claims it becomes easier to explain the long-term increase in DLA numbers.

In essence, incapacity benefits have absorbed much of the slack in the labour market arising from shortfalls in job opportunities. The older industrial areas that now dominate the IB and DLA claimant figures did not always have large numbers out of the labour market on incapacity benefits, even though they have long had above-average numbers affected by ill health. A generation ago, when the older industries were still working, the incapacity claimant rates in these places were far lower. It was only after large-scale job losses set in that incapacity claims began to rise.

This diversion onto incapacity benefits happens slowly and incrementally. Much of it reflects long-term “filtering” in a competitive labour market—it is those with poor qualifications, low-grade work experience and, crucially, poor health or disability who find it hardest to keep a foothold in the world of work. Over time, as this filtering takes place, worklessness shifts from conventional unemployment on Jobseeker's Allowance (JSA) to incapacity benefits. This process is well documented.<sup>78</sup>

The long period of economic growth from the early 1990s to 2008 only partially halted this process: the initial impact was to reduce the number of unemployed on JSA, who are closest to the labour market, and only after JSA numbers had been reduced to historically low levels (by around 2003) was there any fall in the headline IB numbers.

Filtering also works within the stock of IB claimants. While many stay on IB virtually indefinitely, some do return to work, and the men and women with less severe health problems or disabilities are likely to be disproportionately represented among the off-flow. Over time, the IB claimant group therefore becomes more dominated by those with relative severe physical or mental obstacles to working, and it is this group that has accessed DLA. Rising awareness of DLA (which was only introduced in 1992) has probably contributed further.

So the causation runs from a weak labour market, especially in Britain's older industrial areas, through to rising IB claims and thence to rising DLA claims. That DLA claims do not come to an end at state pension age or on returning to work (unless a change of circumstances is recorded) adds a further upward twist.

#### *The implications for the introduction of PIP*

The two key elements in the proposal to replace DLA by Personal Independence Payments are:

- A new more formal assessment procedure to reduce eligibility compared to DLA—to “ensure that support goes to those with the greatest need” in DWP's own words.
- More regular reviews of all PIP awards “to ensure that everyone continues to receive the correct level of award”.

The introduction of a new assessment procedure is analogous to the replacement of the Personal Capability Assessment for IB by the new, tougher Work Capability Assessment for ESA, which is now leading to major reductions in incapacity claimant numbers. The introduction of regular reviews is a significant departure from practice with DLA, where a third of new awards and two-thirds of the stock of claims were “indefinite”.

It is to be expected that the proposed reforms will have a substantial impact on DLA/PIP numbers among the working-age group for whom PIP is initially to be introduced. The actual magnitude of this impact cannot however be assessed at this stage.

<sup>78</sup> See for example C Beatty and S Fothergill (2005). “The diversion from ‘unemployment’ to ‘sickness’ across British regions and districts”, *Regional Studies*, vol 39, pp 837–854.



If the new rules are operated effectively, the main impact can however be expected to fall on a highly specific group: those whose health problems or disabilities are currently sufficient to qualify them for DLA but not quite severe enough to qualify them for PIP. This group will lose entitlement. Some of them will be existing DLA claimants. Others will be men and women who in the future would have claimed DLA.

The majority of working-age DLA claimants also claim IB/ESA, as noted earlier, so the main impact of the introduction of PIP is likely to be felt by claimants who are out-of-work. Moreover, IB and ESA are themselves in the process of reforms that will restrict eligibility. Partly this is a result of the new Work Capability Assessment but the government also intends, from 2012 onwards, to restrict eligibility for non-means tested ESA to one year. This latter reform will have the effect of denying benefit to many claimants with other sources of household income, such as a partner in work or a personal or company pension.

In effect, large numbers of claimants could therefore face a “double whammy”:

- Loss of IB/ESA.
- Loss of DLA.

This loss is possible even in circumstances where there has been no improvement in health or disability and where there continue to be significant mental or physical obstacles to employment. Means-tested benefits (JSA or ESA) will remain as a fall-back to prevent complete destitution. However, for many who have been able to combine IB and DLA, and perhaps other modest sources of household income, to sustain a lifestyle just above the poverty line, that option will now disappear.

These impacts will not be felt evenly around the country. Given the concentration of DLA and IB claimants in Britain’s older areas in particular, it is these places where the impacts on well-being and incomes will be most acutely felt. These are also the places where, owing to continuing shortfalls in job opportunities, former incapacity claimants stand the least chance of finding employment.

#### *Are reforms justified?*

That DLA has become a very substantial burden on the Exchequer is undoubtedly correct. DWP quotes a figure of £12 billion a year spent on this benefit, and there is no obvious reason to dispute this estimate.

It is hard to argue against the regular re-assessment of DLA claims. Indeed, the Sheffield Hallam University report noted: “it is less obvious that, once a DLA claim has been approved, there is regular monitoring that it continues to be justified”.

The case for stricter eligibility rules is however more questionable. As the Sheffield Hallam University report noted “in theory at least, the eligibility rules are already very stringent, for example requiring guidance or supervision out of doors to qualify for the lower rate mobility component, and help or supervision with basic day-to-day tasks to qualify for the lower rate care component”.

There is also little reason to suppose that fraudulent claims are widespread. Again in the words of the Sheffield Hallam University report, “since eligibility for DLA is determined by Department of Work and Pensions officials on the basis of evidence from GPs, hospital consultants and in some cases a medical examination, the scope for outright fraud seems limited”.

#### *Is there a better way forward?*

The answer here is certainly “yes”.

The problem is that the proposed reforms start from the assumption that eligibility for DLA has simply become too generous. However, if instead the large number of non-employed DLA claimants of working age is understood as part of the wider issue of large numbers on IB (or its successor ESA), as the Sheffield Hallam University evidence suggests, the approach to reducing DLA numbers needs to be rather different.

First, practical support and advice needs to be available to help DLA claimants (and IB claimants more generally) re-engage with the labour market. At present, only a minority of DLA claimants express an interest in working again—rather less than 250,000 according to estimates in the Sheffield Hallam report, though that remains a substantial number. Looking ahead, however, the introduction of ESA, with its new element of conditionality, should begin to erode the bigger numbers that have given up on the idea of ever working again. Even so, it is not clear that scale and duration of the interventions needed to move DLA claimants closer to the labour market have been fully anticipated. DLA claimants are in many respects the most challenging group among IB claimants. To re-engage with the labour market they require not only advice and training of the kind traditionally provided by employment services but also sustained access to the physical and mental rehabilitation services that have traditionally been the preserve of the National Health Service.

Second, jobs need to be available in the right places and in the right numbers to absorb claimants who move off IB and DLA (or indeed are diverted from moving onto these benefits in the first place). This is largely a task of local and regional economic development. Having the right national economic context matters as well,

but as the evidence from the most prosperous parts of southern England demonstrates very clearly, where the economy has been strong over many years and where there are plentiful job opportunities, few men and women need to claim either IB or DLA.

5 September 2011

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### Written evidence submitted by the Department for Work and Pensions

#### INTRODUCTION

1. The Government is committed to supporting disabled people to exercise choice and control and lead independent lives and recognises that disabled people face extra costs in so doing. Disability Living Allowance (DLA) helps to deliver on this commitment. However, there has been a growing consensus from across the political spectrum and from disability representative organisations that this benefit is no longer in step with the needs of disabled people, and that it is not sustainable over the long-term.

2. The Government announced in the June 2010 Budget that it would reform DLA to help those facing the greatest barriers to living independent lives, while making sure that the benefit remains affordable and sustainable.

3. On 6 December 2010, the Government published the consultation document, *Disability Living Allowance reform*, and began a formal consultation on proposals to replace DLA with a new benefit called Personal Independence Payment.<sup>79</sup> The document set out the need to reform DLA and asked for views to inform the policy for the new benefit and the introduction of a more objective assessment.

4. The Government understands the value and importance of involving disabled people and their representatives in the reforms by providing a genuine opportunity to influence decisions. Since the Budget announcement, Ministers and officials have met with disabled people, their families and disability organisations, at both a national and local-level, to seek input to the reform proposals. The Department has also set up an Implementation Development Group specifically for customer representatives to contribute to the design and development of the operational processes needed to deliver the new benefit. Throughout the process the Department has worked together with the Office for Disability Issues to identify how grass-roots disabled people's user-led organisations can be involved in the implementation design and development work. This work is ongoing and remains an integral part of the design and development of Personal Independence Payment.

5. The formal consultation period closed on 18 February 2011. The Department received more than 5,500 responses to the consultation, including nearly 5,000 from individuals. Around half of responses from individuals were standard responses,<sup>80</sup> and more than 500 responses from organisations.

6. The Government published its response to the consultation on 4 April 2011.<sup>81</sup> This outlined the responses received and provided further information about the reforms. The Government confirmed that Personal Independence Payment would be introduced for people of working age (aged 16–64) for both new and existing claims from 2013, and reaffirmed their commitment that it would remain a non-contributory, non-means-tested cash benefit to contribute to the extra costs of disability.

7. On 9 May 2011 the Department published initial draft regulations for the Personal Independence Payment assessment criteria to inform consideration of the Welfare Reform Bill.<sup>82</sup> An explanatory technical note accompanied the draft criteria which outlined plans for refinement and testing to inform the policy on which the Department has asked for feedback through an informal consultation. The Department also published a series of policy briefing documents, which set out key elements of the policy proposals relating to the reform of DLA and the design and administration of Personal Independence Payment. These included briefing notes, for example, on the operational approach and award durations.

8. The high-level legislative framework underpinning Personal Independence Payment is set out in the Welfare Reform Bill which is currently before Parliament. The Government's intention is that the detailed requirements for the new benefit will be set out in secondary legislation and that responses to the DLA reform consultation and the informal consultation on the assessment, along with continued engagement with disabled people and disability organisations, will be used to inform the detailed design.

9. The policy, including the draft assessment criteria, is continuing to be developed through testing as well as current and planned consultation with disabled people and their representatives. The Government acknowledges that there is still a great deal of work to do to ensure the reforms work as intended. This is an iterative process and some of the detailed proposals and delivery processes will continue to evolve during the period of the Committee's inquiry.

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<sup>79</sup> *Disability Living Allowance reform*, Cm 7984, December 2010.

<sup>80</sup> A standard response was defined as two or more emails or letters that contained the same text, but were signed by different individuals.

<sup>81</sup> *Government's response to the consultation on Disability Living Allowance reform*, Cm 8051, April 2011.

<sup>82</sup> <http://www.dwp.gov.uk/policy/welfare-reform/legislation-and-key-documents/welfare-reform-bill-2011/personal-independence-payment-briefing/>.

10. The Government has already acted on feedback received both during and following the consultation and has made changes to the original policy:

- Following responses to the DLA reform consultation, the Government announced that Personal Independence Payment will not be extended to new or existing claims for children from 2013/14 and the Government has committed to consult before extending Personal Independence Payment to children.
- The DLA mobility component will not be removed from people in residential care in 2012. The Government will consider the needs of people living in residential care at the same time as all other DLA recipients as it develops Personal Independence Payment for introduction in 2013.
- As well as learning from the Harrington review of the Work Capability Assessment,<sup>83</sup> the Government has committed to a review of the operation of the new assessment, reporting within three years of the primary legislation coming into force.

11. The Department will ensure that the Committee is kept informed of developments and made aware of further publications during the course of its inquiry.

#### THE NEED FOR DISABILITY LIVING ALLOWANCE REFORM

12. Disability Living Allowance was introduced in 1992 and has not been fundamentally reviewed or reformed since. The caseload increases have exceeded projections and there is confusion about the purpose of the benefit. DLA is a complex benefit to claim and administer and there is no systematic way of checking that awards remain correct.

13. The main reasons underpinning the Government's reform of DLA are that:

- the public, claimants, and in some cases their advisers, do not understand what the benefit is for—many perceive it as compensation for being disabled, linked to being out of work or poor;
- the current assessment process means awards can be inconsistent and lack credibility amongst disabled people themselves. This results in a large number of complaints and appeals and a large body of case law has developed, which can be difficult to interpret;
- the system lacks consistency in the way it supports disabled people with similar needs, and decision making on awarding the benefit can be subjective;
- people's conditions can change over time—however, there is no systematic or straightforward way of reviewing people's entitlement to DLA on a regular basis to ensure that they receive the right level of benefit. More than 70% of the current DLA caseload has an indefinite award;<sup>84</sup> and
- there is a need to get expenditure on a sustainable footing; over the last decade spending on DLA has risen dramatically. In just eight years the number claiming the benefit has risen from around 2.5 million to nearly 3.2 million—an increase of nearly 30% (February 2011).<sup>85</sup> The total amount spent on the benefit this year is forecast to be £12.6 billion.<sup>86</sup> This is significantly higher than envisaged.

14. Reform of DLA is part of the Government's wider objectives to build a welfare system based on the principles of fairness and responsibility, which protects the most disadvantaged, and is financially sustainable.

15. The policy objectives that underpin the introduction of Personal Independence Payment are to:

- retain the main features of DLA that disabled people value—for example, Personal Independence Payment will be a non-means tested and non-taxable cash benefit for people to spend as they choose, and it will be available to people both in and out of work;
- create a new benefit that is more dynamic and responsive to changes in individual needs;
- target support on disabled people who face the greatest barriers to leading full and active lives;
- assess entitlement in a manner that is fairer, more transparent, more objective and more consistent than the current DLA processes; and
- make the new benefit simpler to administer, easier to understand and more transparent.

#### *DLA: How well it is understood*

16. The Department has conducted thorough research and analysis into the views of DLA claimants. Disabled people and their representatives have reported that the current system is complicated and the claim form is long, and overly repetitive. Claimants are unclear about whether or not they are likely to qualify<sup>87</sup> and there is evidence that people awarded DLA do not fully understand the purpose of the benefit.<sup>88</sup> For example, some

<sup>83</sup> Harrington M, 2010, *An Independent Review of the Work Capability Assessment*, TSO.

<sup>84</sup> DWP Ad Hoc Analysis, *Analysis of Disability Living Allowance: DLA Awards*, March 2011.

<sup>85</sup> DWP Ad Hoc Analysis, *Disability Living Allowance: Growth in the Number of Claimants 2002–03 to 2010–11*, August 2010.

<sup>86</sup> [http://research.dwp.gov.uk/asd/asd4/alltables\\_budget2011.xls](http://research.dwp.gov.uk/asd/asd4/alltables_budget2011.xls).

<sup>87</sup> *Disability Living Allowance and work: Exploratory research and evidence review*, 2010, DWP Research report No.648.

<sup>88</sup> *The impact of Disability Living Allowance and Attendance Allowance: Findings from exploratory qualitative research*, 2010, DWP Research report No. 649.

view the benefit as a form of compensation for being disabled, while others do not in fact view themselves as disabled.

17. A significant number of claimants believed that DLA was only for people who are out of work and that starting work would lead to a review and subsequent loss of benefit. This suggests that DLA can act as a barrier to work instead of enabling people to live independent and active lives—a key aim of Personal Independence Payment.

18. The current assessment process for DLA consists of a claim form completed by the individual, which is considered by a Decision Maker in the Department. This process is based on unclear criteria and often does not make the best use of the evidence that is available. Consequently awards can be subjective and inconsistent; meaning that the benefit is not well targeted on those who need it most.

19. Independent research published by the Department in 2008 showed that there was an overall disallowance rate for DLA of 52%.<sup>89</sup> This level of disallowances suggests that a high proportion of claims are being made that have very little chance of succeeding. The research shows that most applicants knew little or nothing about DLA before making their application and that there were a high proportion of speculative claims. Disallowances included cases where applicants had either failed to meet basic eligibility criteria, or had failed to show they had the care and mobility needs that would entitle them to the benefit. More recent Departmental analysis shows that the proportion of disallowed DLA claims remains at around 50%.<sup>90</sup>

#### *Why the DLA caseload and expenditure has increased*

20. The total caseload on DLA, including children and those aged over 65 has increased from 1.1 million in 1992–93 to 3.2 million in 2010–11. Expenditure has increased from £3.2 billion to £12.3 billion (2011–12 prices) during the same period. In just eight years the numbers of people receiving DLA has increased by around 30% (August 2010).<sup>91</sup>

21. Overall, growth in DLA has been driven partly by the age entitlement rules, with the benefit maturing as more and more individuals retain their DLA claim beyond the age of 65. The growth in pensioners receiving DLA is largely driven by the fact that claims for DLA have to be made before age 65. This means that each year the maximum age at which it is possible to receive DLA increases by one year. However, some of this growth in over 65s is due to the widening of the eligibility criteria when the claims were made. There has also been a significant growth in the DLA caseload for children which cannot be attributed to demography.

22. Working age (16–64) expenditure has risen from £2 billion in 1992 to £6.7 billion in 2010–11 (2011–12 prices). Growth is driven partly by demographics but also by increases in the *per capita* rate. There are several factors which could have increased the take-up of DLA. For example, as the benefit has aged it is likely that knowledge of DLA as a benefit for disabled people has increased.

23. Over time a large amount of case law has grown up around the benefit. This has widened the interpretation of the eligibility criteria for DLA by increasing the number of different factors that may be taken into account, making the benefit less targeted and available to far more people than originally intended, and resulting in inconsistent awards.

24. The complexity and subjectivity of benefit decisions has led to a broader interpretation of the legislation and this has been exacerbated by a heavier reliance on self-reporting and indefinite benefit awards than originally intended. The introduction of the lowest rate of the care component in 1992 for example was estimated to help 140,000 people; however, today there are 890,000 people in receipt of lowest-rate care.<sup>92</sup>

#### *The effectiveness of the decision-making and review process for DLA*

25. The Pensions, Disability and Carers Service (PDCS) are responsible for the administration and payment of DLA. Staff handle around 450,000 new claims, over 250,000 renewal claims and around 300,000 reviews, reconsiderations and supersessions every year.<sup>93</sup>

26. Current practices can leave recipients of DLA on the benefit for years at a time without checking whether they are still entitled or should have their rate of benefit adjusted. For example, the 2004–05 National Benefit Review found that around £630 million was being overpaid and around £190 million was being underpaid to claimants as a result of unreported changes in circumstances.<sup>94</sup> 24% of working age (16–64) DLA claimants have either not had a change to their award, or their award looked at, for a decade.<sup>95</sup>

<sup>89</sup> *Disability Living Allowance: Disallowed claims*, 2008, DWP Research report No 490.

<sup>90</sup> <http://www.publications.parliament.uk/pa/cm200910/cmhansrd/cm100322/text/100322w0009.htm>.

<sup>91</sup> DWP Ad Hoc Analysis, *Disability Living Allowance: Growth in the Number of Claimants 2002–03 to 2010–11*, August 2010.

<sup>92</sup> Department for Work and Pensions, Information Directorate: Work and Pensions Longitudinal Study, Feb 2011 [http://83.244.183.180/100pc/dla/tabtool\\_dla.html](http://83.244.183.180/100pc/dla/tabtool_dla.html).

<sup>93</sup> A renewal is where an individual makes a new claim from the expiry of an award. Reviews, reconsiderations and supersessions broadly concern re-examining an award and potentially making a new determination—for example this can be triggered by the report of a change of circumstances.

<sup>94</sup> *Fraud, error and other incorrectness in Disability Living Allowance: The results of the Benefit Review of Disability Living Allowance*, 2005.

<sup>95</sup> DWP Ad Hoc Analysis, *Analysis of Disability Living Allowance: DLA Awards*, March 2011

27. In order to create greater fairness, Personal Independence Payment will have a more objective assessment, usually via face-to-face consultations, and with a more regular intervention strategy to ensure that the decision making process is, and remains, as robust, consistent and fair as possible.

#### *Appeals*

28. A lack of understanding of the benefit and unclear criteria that can result in inconsistent awards, is a contributing factor to a large number of appeals. In 2009–10, 214,000 people were awarded DLA as a new claim, 267,000 people were disallowed and 36,000 appeals were submitted, of which 14,000 (39%) were overturned.<sup>96</sup>

29. It is concerning that the main reason given by tribunal panels for overturning the original decision is that new evidence was presented. According to a Report by the President of the Social Entitlement Chamber, 72% of the DLA/Attendance Allowance decisions overturned at tribunal, are overturned due to additional evidence being provided.<sup>97</sup>

30. The Department wants to work with disabled people to ensure that the right evidence is collected during the claim stage, in order to allow the Decision Maker to make an informed decision. The Department will consider ways of improving contact between the claimant and Decision Maker, particularly during the new mandatory reconsideration process proposed in the Welfare Reform Bill, so that the Department understand why claimants feel their original decision may be incorrect, handle appropriately and provide a more detailed explanation of the reasons the decision has been reached. The increased engagement and mandatory reconsideration will give the Department an opportunity to correct errors in decisions, something that does not always happen under the current process.

#### *Why not improve the existing system?*

31. Reform of the welfare system has traditionally been piecemeal, resulting in a confusing array of additions and exceptions bolted on to an outmoded system. The systems behind DLA are similarly outdated. The IT system is extremely basic, claims involve a large amount of paper and administrative processes are labour intensive. These reforms presented an ideal opportunity to start afresh, keeping the best elements of DLA that disabled people value, but bringing the benefit into the 21st Century.

32. The name of the new benefit is intended to better reflect its purpose and to move away from a system that awards entitlement for certain conditions to a benefit that treats each application individually and reflects our commitment to support disabled people and enabling them to lead full and active independent lives.

#### IMPORTANCE OF GETTING MONEY TO THE RIGHT PEOPLE

33. In designing Personal Independence Payment, the Government has been mindful of the current fiscal position, and the need to ensure the benefit remains sustainable in the long term. The Government expects that the changes will result in projected working-age expenditure in 2015–16 being 20% lower than it would be without the reform of Disability Living Allowance, containing projected expenditure in 2015–16 to 2009–10 levels. Even following the introduction of Personal Independence Payment, it is likely that there will continue to be some increase in expenditure due to demographic and other factors, such as an ageing population.

34. The effect on the working-age (16–64) DLA caseload cannot be quantified at this stage as the draft assessment criteria for Personal Independence Payment are still being tested. Reducing expenditure by 20% does not equate to a reduction in awards of 20%; it may be more or less depending on the impact of the assessment on rate combinations. Some might receive a higher award on one component and a lower award on the other component. More detail on the impact on the caseload will be provided once further work to develop and test the assessment criteria is complete.

35. A clear objective of the reforms is to simplify the benefit. One way in which the Government hopes to achieve this is through changing the overall structure of the benefit. The intention is that Personal Independence Payment will have two components: the Daily Living and Mobility components and that each will have two rates—standard and enhanced. This will reduce the current eleven different rate combinations to eight. This will make Personal Independence Payment simpler to administer and easier for everyone to understand, while continuing to reflect the range of individual needs.

36. These structural changes will also remove areas of overlap in the current system between the lower rate mobility component and the care component. At present, the higher and lower rates of the DLA mobility component are based on different criteria. With the exception of some automatic entitlements, higher rate mobility is generally awarded for physical health conditions or impairments, whereas lower rate mobility is linked to the need for supervision or guidance when outdoors. This means that there is some overlap between the lower rate mobility and the care component, as the care component is largely based on the need for supervision or attention. In the new assessment, there will be separate criteria for each component, based on an individual's ability to carry out certain everyday activities. These criteria will determine entitlement to both

<sup>96</sup> DWP Ad Hoc Analysis, *Analysis of Disability Living Allowance: DLA Awards*, March 2011.

<sup>97</sup> The Tribunals Service, *Report by the President of the Social Entitlement Chamber of the First-tier Tribunal on the standards of decision-making by the Secretary of State and Child Maintenance and Enforcement Commissioner*, 2010.

the standard and enhanced rates of the component, depending on the cumulative impact of an individual's health condition(s) or impairment(s).

37. There has been some concern that, as a result of structural changes, individuals currently in receipt of the lowest rate of the DLA care component will not be eligible for Personal Independence Payment. This is simply speculation. Entitlement to Personal Independence Payment will be based on an assessment of the impact of an individual's health condition or impairment on their ability to carry out everyday activities. It is, therefore, not possible to say whether individuals in receipt of a particular rate of DLA will or will not be eligible for Personal Independence Payment; it will depend on their individual circumstances. At this stage it is too early to make any evidence-based assessment of the impact of the reforms on the existing DLA caseload. There will be more detail on the likely impact of the assessment in the autumn following completion of the testing of the initial draft of the criteria and analysis of the results.

#### THE EXTENT TO WHICH OVERLAPS IN FUNDING EXIST

##### *Duplication of Provision in Hospitals, Care Homes and Prisons*

38. Disability Living Allowance provides an important cash contribution towards the disability-related extra costs of those disabled people who have the most complex support needs. Avoiding overlaps in funding and thereby ensuring the tax payer does not pay twice for the same need is a fundamental principle of Government.

39. The primary intention of the DLA hospital and care home rules is to prevent the duplication of provision that would otherwise arise if disability-related extra costs benefits were paid at the same time as those costs were being met from public funds.

40. Currently, where a person is maintained free of charge while undergoing medical or other treatment as an in-patient in a hospital or similar institution, payment of the care and mobility components of DLA stops after 28 days. This is because the NHS is responsible for meeting all of the disabled person's disability related needs. Children in hospitals are afforded a longer period—84 days—as it is acknowledged that they require a longer transitional period to settle in, including greater contact with and support from their parents.

41. For residents of care homes payment of the DLA care component stops after 28 days because the Local Authority is responsible for meeting those needs in full.

42. Continued payment of the benefit in the circumstances described above is made to help someone meet any outstanding disability-related costs and to avoid a break in the claim during short periods of hospitalisation or respite care. Individuals who are affected by these rules retain an underlying entitlement to the benefit, which will be reinstated when they leave the care home or hospital and continue to satisfy eligibility conditions.

43. Disabled people who pay for all care home costs themselves or who are full private patients in hospital would continue to be paid any DLA they are entitled to as there is no double provision of funds.

44. The Government believes there is a principled case that, to avoid duplication of provision, payment of benefit should cease when someone is placed in legal custody in any circumstances. This also applies in the case of prisoners who have all of their disability-related needs met by either the prison itself or through healthcare provided by the Primary Care Trust.

45. There have been some suggestions that the reform of DLA will increase the burden on the NHS and Local Authorities, as individuals who are ineligible for Personal Independence Payment seek other sources of support. Access to support services through the NHS and Local Authorities is not dependent on receipt of DLA. The Government expects individuals who require these services to be accessing them already and therefore does not believe these reforms will have an adverse impact on the NHS or Local Authorities.

46. Disability benefits are only one part of the package of support available to disabled people. For example, the Government has already demonstrated its continued commitment to the Work Choice employment programme, the Disabled Facilities Grant and the Supporting People programme, all of which provide alternative sources of support.

##### *Disability Living Allowance Mobility Component in Residential Care*

47. The Spending Review included a measure, which would have meant that the mobility component of Disability Living Allowance would cease to be paid to all state funded residents in care homes after 28 days from October 2012.

48. A great deal of concern has been expressed about this proposal and as a result the Government has given a commitment that it will not remove the DLA mobility component from people in residential care in 2012. It will consider the needs of people living in residential care at the same time as all other DLA recipients as it develops Personal Independence Payment for introduction in 2013.

49. The Government will ensure that when it introduces Personal Independence Payment from April 2013 it treats disabled people fairly, regardless of their place of residence; and does not reduce disabled people's ability to get out and about.

50. Officials in the Department for Work and Pensions are considering existing evidence and gathering more to determine the extent to which there are overlaps in provision for mobility needs of people in residential care homes. This work should be completed soon and the Government will then make a final decision on the way forward. What is important is that disabled people are able to get out and about and live independently.

#### AUTOMATIC ENTITLEMENT AND AWARD DURATION

##### *Automatic entitlement*

51. The Government recognises that people lead varied and often complex lives, with differing circumstances and needs, and that health conditions and impairments can affect people in very different ways. The Government does not think it right that people should be judged purely on the type of impairment they have, labelling them on this basis and making blanket decisions about benefit entitlement. Such an approach can lead to individuals receiving levels of support that may not reflect their needs. The intention is that Personal Independence Payment should provide support tailored to an individual's personal circumstances.

52. Disability Living Allowance currently provides automatic entitlement for individuals with severe mental impairment or who are double amputees, deaf/blind, severely visually impaired, those undergoing haemodialysis and those claiming through Special Rules. While in some cases it might not be necessary to see people at a face-to-face consultation, in many cases it might be the only way to properly assess their needs. There is a need to consider people on a case-by-case basis.

53. The Government's intention is, therefore, that there will be no automatic entitlement within Personal Independence Payment based on someone's condition, diagnosis or treatment plan. Special Rules for individuals who are terminally ill will, however, remain, providing a fast track service to the enhanced rate of the daily living component, and removing the requirement for them to undergo assessment for their daily living needs or meet the Required Period Condition. The proposal is instead that everybody claiming Personal Independence Payment will undergo an assessment by a trained health professional to help determine whether they should receive the benefit and the components and rates payable. This assessment will treat people as individuals, considering the impact of their health condition or impairment on their everyday lives, rather than basing entitlement on their medical condition.

54. The Government believes that an important part of the Personal Independence Payment assessment process for most individuals should be a face-to-face consultation with the assessor. This will allow an in-depth look at the individual's circumstances and give them the opportunity to put across their own views of the impact of their impairment on their everyday lives. This may also provide the opportunity to signpost individuals to other forms of support or advice available of which they may not be aware.

55. While most people will have a face-to-face consultation, the Government does not believe that this will be necessary in all cases. For example, where there is already sufficient evidence available to strongly support a decision on benefit entitlement, requiring individuals to attend a consultation may be unnecessary. In these circumstances, making an assessment based on paper evidence might be more appropriate. The Government believes, however, that such decisions on whether a face-to-face consultation is necessary, should be made on a case-by-case basis, considering the available evidence, not on the basis of the health condition or impairment individuals have.

56. Assessments will be delivered by a third party contracted to the Department and commercial activity is scheduled to begin shortly.

##### *Award durations*

57. The individualised approach the Government is proposing in Personal Independence Payment also applies to award durations. It is important to recognise that individuals' circumstances and the impact of health conditions and impairments can change over time. The length of awards of Personal Independence Payment should reflect this, making the benefit more responsive to changing needs than DLA. Seventy per cent of current DLA awards are for an indefinite period, while around 130,000 people who were transferred to DLA from predecessor benefits in 1992 have never had their awards changed.<sup>98</sup> Not reviewing these claims means that some people whose needs may have changed might not be getting the support they need.

58. The 2004–05 National Benefit Review of Disability Living Allowance identified that there were a number of people in receipt of DLA who were receiving an incorrect award.<sup>99</sup> Although only a small proportion of this was due to fraud or official error, the review identified that £630 million (or 11.2% of cases) was overpaid because of these changes in claimants' circumstances. It also found that £190 million (or 6.3% of cases) was underpaid to individuals for the same reason. This was not classified as fraud: the individuals' circumstances had changed so gradually that they could not be expected to have known they needed to report a change.

<sup>98</sup> DWP Ad Hoc Analysis, *Analysis of Disability Living Allowance: DLA Awards*, March 2011.

<sup>99</sup> *Fraud, error and other incorrectness in Disability Living Allowance: The results of the Benefit Review of Disability Living Allowance*, 2005.

59. For Personal Independence Payment, awards will generally be for a fixed period, with the length of the award based on the likelihood of an individual's circumstances changing. Some awards will continue to be made on an ongoing basis, without a fixed end date, where appropriate—for example, if an individual has a severe and degenerative condition. In deciding whether a fixed-term award would be inappropriate, a Decision Maker must have regard to guidance issued by the Secretary of State. The Government believes that decisions on award length should be based on individual circumstances and not be based upon the type of health condition or impairment people have, as these can vary in their severity and impact. Meanwhile, individuals may adapt to their circumstances and overcome barriers that prevent participation or lead to higher costs. Guidance regarding award durations will be made available to assessors and Decision Makers and be informed by medical expertise.

60. The Department will also periodically review both ongoing and fixed-term awards to ensure that no change of circumstance has occurred which could affect entitlement or the rate of benefit currently in payment. This approach will ensure that individuals continue to receive the right support from Personal Independence Payment.

#### A SIX MONTH QUALIFYING PERIOD

61. The Government's priority is to target support on those individuals with long-term health conditions or impairments so that they can lead full, active and independent lives. A required period condition of 12 months with a six month qualifying period and six month prospective test will help to achieve this aim.

62. The principal aim of extending the qualifying period from three to six months is to align the definition of long term disability with the Equality Act 2010. The Government does not expect this measure to provide any significant savings. As now, most people will not have to wait six months before being paid Personal Independence Payment if some or all of the qualifying period has been satisfied by the time they submit their claim. For example, if someone submits their claim for Personal Independence Payment three months after they would have satisfied the entitlement conditions they may become entitled three months after the claim was made.

63. People who are classified as terminally ill (who are expected to die within the next six months) will not have to serve a required period condition. This will allow for financial support to those in the most difficult circumstances to start as quickly as possible by exempting them from the qualifying period and prospective test.

64. The Government is also proposing that disabled people who have a fluctuating condition, which may result in a short break of entitlement to Personal Independence Payment, will not have to fulfil another qualifying period if they reclaim the benefit as a result of deterioration in their condition, within 12 months.

65. The six month qualifying period is not intended to deny disabled people financial help in the short term. For those in lower income groups, particularly those with little or no connection to the labour market, that help currently comes from mainly, but not exclusively, means-tested benefits. Personal Independence Payment will be a valuable, universal benefit. It is only right that the Government balance the needs of those who can be expected to meet additional costs in the short term with those who cannot.

#### THE EXTENT TO WHICH PERSONAL INDEPENDENCE PAYMENT WILL ACT AS A GATEWAY TO OTHER BENEFITS

##### *Carer's Allowance*

66. The highest and middle rate of the care component of Disability Living Allowance currently provide access to Carer's Allowance, once they are caring for someone over 35 hours a week. The Government recognises the importance that carers and those they care for place on this gateway to Carer's Allowance.

67. The Government acknowledges that receipt of Personal Independence Payment remains the least complex and most cost effective gateway to Carer's Allowance, and so it will act as a condition of entitlement for Carer's Allowance as DLA currently does.

68. While Personal Independence Payment will provide a gateway for receipt of Carer's Allowance, the Government is not able to confirm, at this stage, which rate(s) of the daily living component of Personal Independence Payment will be used for this gateway. It is only when the Department has fully developed and tested the new assessment that the decision can be made.

69. The work to develop the detailed criteria for the assessment is ongoing with formal testing of the assessment having taken place over the summer. Robust modelling of the implications of using the standard and/or the enhanced rate of Personal Independence Payment for the gateway to Carer's Allowance will be linked to this testing and the results of which should better enable the Government to decide which rate(s) should be used to determine Carer's Allowance eligibility.

##### *The Motability Scheme*

70. The Motability scheme enables disabled people with the most complex support needs in receipt of the higher rate mobility component of DLA or War Pensioners Mobility supplement to lease or buy a car, powered wheelchair or scooter in exchange for some or all of their benefit.



71. Motability have confirmed that they want the mobility component of Personal Independence Payment to act as a passport to the scheme. Discussions are still underway to determine the precise rate that will provide access to the Motability scheme. The Department will continue to work closely with Motability, who remain committed to helping those disabled people who face the greatest barriers to independent living, and aim to finalise details in the autumn.

#### *Blue Badge and other, non-DWP passports*

72. DLA currently acts as a passport to a wide range of additional support provided by other government departments, the Devolved Administrations, Local Authorities and other national or local providers. Some of these passports have statutory links, such as to the Blue Badge (Disabled Persons Parking) scheme or to Energy Efficiency Grants, whilst others are covered by statutory guidance, such as concessionary travel, or voluntary arrangements only, for example free cinema tickets for a carer.<sup>100</sup>

73. In most instances the link through to receipt of DLA, whether by reference to the benefit generally or to a particular component and/or rate, is for administrative simplicity and efficiency: receipt of DLA acting as a straightforward method to identify disabled people without having to assess them twice and administrators having to pay for a duplicate assessment. For example, over 850,000 disabled people currently benefit from the automatic link between the Higher Rate Mobility Component of DLA and award of a Blue Badge.

74. The Department will ensure that external bodies and other government departments are aware of the introduction of Personal Independence Payment from 2013 so they can amend their systems and information accordingly. The Department wants to ensure that, as now, people with the greatest barriers to participation are able to access other services and support as easily as possible and appropriate passporting links are able to be maintained.

75. The intention is that individuals will receive an award letter, as now, which would continue to act as confirmation that they were in receipt of particular component(s) of Personal Independence Payment at a particular rate. The Department will continue to work with colleagues across government, the Devolved Administrations and Local Authorities to identify further opportunities for streamlining this process and where possible maximising efficiencies through effective use of IT and business processes.

#### DESIGN OF THE ASSESSMENT

##### *The Disability Living Allowance Assessment Process*

76. As society changes and our knowledge and understanding of barriers to participation develop it is essential that an assessment for disability benefit keeps pace. However, this has been particularly difficult to achieve in Disability Living Allowance as the majority of the entitlement criteria are enshrined in primary legislation—Social Security Contributions and Benefits Act 1992. This has made it very difficult to revise the benefit in a timely way as seen most recently whilst extending the Higher Rate Mobility Component to severely visually impaired people. Such an approach to policy maintenance must be revised.

77. The current assessment also comes under criticism regarding its treatment of claimants with mental health conditions. The structure of DLA means that only certain conditions or impairments can receive certain rates of the benefit. For example, high rate mobility is only available to those individuals who are physically unable to walk not to those with mental health conditions. Such an approach has led claimants with non-physical impairments, to suggest that they feel “second class” to those with physical impairments. As stated, the criteria are also very subjective and have become widened over time by a number of case law judgments allowing the original intentions on the benefit to be lost in time.

78. Apart from the impact of the legal framework of DLA, the current assessment process itself is confusing, inconsistent and anachronistic. DLA is largely self-assessed through the completion of a lengthy self-assessment paper claim form; additional medical evidence is only gathered in around half of all cases;<sup>101</sup> the administrative processes are largely paper-based, resulting in high administrative costs; and, inconsistent decision making due to the subjective nature of the criteria leads to different awards being made resulting in a high volumes of appeals—which again leads to greater administrative costs.

##### *Approach to the assessment*

79. The purpose of the new assessment for Personal Independence Payment is to allow the Department to determine entitlement to the benefit in a more accurate, objective and consistent way than happens in DLA, ensuring that the benefit is focused on those with the greatest need.

80. The Department firstly considered whether it would be possible to assess the actual costs incurred by disabled people. However, the available evidence shows that there is a lack of consensus on what these costs are and how they can be calculated—for example, how you can disaggregate disability-related costs from other everyday costs. The Department therefore felt that developing an assessment based on actual costs would provide subjective and inconsistent outcomes which do not align with the aims of Personal Independence

<sup>100</sup> <http://www.ceacard.co.uk>

<sup>101</sup> DWP Ad Hoc Analysis, *Analysis of Disability Living Allowance: DLA Awards*, March 2011.

Payment. Such an approach would also likely require lengthy and intrusive assessments, which would be complex and expensive to deliver.

81. The alternative to assessing actual costs incurred is to use a proxy for these costs or the impact of disability more widely. Such an approach is used in DLA, which uses care and mobility needs as the proxy, giving priority to those with the greatest needs. While the Government recognises that care and mobility needs are key factors affecting both extra costs incurred and the impact of a health condition or impairment on people's everyday lives, it feels that these are currently narrowly defined and exclude important issues such as communication. It was felt that the assessment for Personal Independence Payment should keep a strong focus on care and mobility, and that it was important that it reflected wider factors and a more modern consideration of the impact of a health condition or impairment.

82. Consideration was also given to whether there is opportunity to build on assessments used in other countries or existing methods of measuring disability, such as the International Classification of Functioning developed by the World Health Organization.<sup>102</sup> Whilst this was helpful to the development work, it did not identify anything which, unaltered, would be appropriate for Personal Independence Payment.

83. Having considered all the options, the Department felt that the best approach would be to develop a set of tailored assessment criteria to act as a proxy for the impact of disablement on individuals and the extra costs this brings. The Department has decided that this proxy should be an individual's ability to participate in everyday life, with priority in the benefit going to those least able to do so.

#### *Assessment criteria*

84. It was decided to measure the ability to participate by assessing individuals' ability to carry out key everyday activities. It would not be practical for the assessment to take account of the impact of health conditions or impairments on all everyday activities, nor to seek to include all possible areas where extra costs may be generated. This would lead to over-complexity and be challenging for consistency, administration and the time needed for assessments. As such the Department and Assessment Development Group<sup>103</sup> have sought to identify a series of key activities that are fundamental to participation in everyday life and which can cumulatively act as a proxy, identifying those individuals who are likely to have the highest level of need.

85. The following eleven key activities were chosen, each relating to one of the two components of Personal Independence Payment:

##### *Daily Living component:*

- Planning and buying food and drink.
- Preparing and cooking food.
- Taking nutrition.
- Managing medication and monitoring health conditions.
- Managing prescribed therapies other than medication.
- Washing, bathing and grooming.
- Managing toilet needs or incontinence.
- Dressing and undressing.
- Communicating with others.

##### *Mobility Component:*

- Planning and following a journey.
- Moving around.

86. These activities have been chosen to provide a more holistic assessment of the impact of disability that the current DLA criteria, taking fairer account of the full range of impairment types, including physical, sensory, mental, intellectual and cognitive impairments. For example, the introduction of communication is a significant departure from DLA and one which will ensure better account is taken of the effect of impairments of hearing, speech and language comprehension.

87. An initial draft of the assessment criteria was published on 9 May 2011, in the form of draft regulations and a supporting technical note.<sup>104</sup> Draft point scores have not yet been included in the draft regulations but will feature in the next draft of the assessment criteria due to be published.

#### *Fluctuating conditions*

88. The Government recognises that it is essential that the assessment for Personal Independence Payment deals effectively with variable and fluctuating conditions.

<sup>102</sup> <http://www.who.int/classifications/icf/en/>

<sup>103</sup> <http://www.dwp.gov.uk/docs/pip-draft-assessment-regulations.pdf> & <http://www.dwp.gov.uk/docs/pip-draft-assessment-criteria-note.pdf>

<sup>104</sup> *Ibid*

89. The assessment will not be a “snapshot” of any one day but will consider an individual’s ability to carry out activities over a period of time, enabling the assessment to capture a reliable picture of how a condition actually affects the individual. The Department’s current thinking is that decisions should be made having considered the impact of impairments over a 12 month period and that it should consider impacts that occur for the majority of the time in that period. If one of the assessment criteria cannot be completed in the way described within the descriptors for more than six months, aggregated over the 12 month period, then it should be viewed as not being able to be completed at all. This process should allow the assessment to take the fluctuations of conditions into account.

90. A further key principle of the assessment is that it must take into account the need for activities to be carried out safely, reliably, repeatedly and in a timely fashion. Where this is not possible, the assessment will consider the individual as not being able to carry out the activity at all.

#### *Aids and appliances*

91. The Government believes that priority in the benefit should go to those individuals least able to participate in everyday life. Therefore, it considers it right that the assessment takes some account of the successful use of aids and appliances. However, such an approach needs to be undertaken sensitively and proportionately, recognising that aids do not remove an individual’s impairment and that there may be additional ongoing costs associated with their use.

92. As an example it is appropriate to highlight the Department’s approach to the use of guide dogs by visually impaired individuals. The Department has no intention of penalising visually impaired people who are only able to get around and live independently with the help of a guide dog. While the support that guide dogs provide is extremely important, they do not of course help an individual to eat and drink, to manage personal care and treatment needs or to communicate with others. In addition, while they do help people get around, they do not in themselves improve the physical ability to walk or the ability to plan a journey.

93. Concern has been raised that taking into account aids and appliances creates incentives for disabled people to not take up aids that might help them. The Government does not consider that there are undue incentives: the approach being taken is proportionate and one that continues to recognise and award points to individuals who can only carry out activities with the help of aids and appliances. It will be entirely possible for individuals who use aids and appliances to receive sufficient point scores to qualify for the benefit, as long as they meet the criteria.

#### *Testing and further developing the assessment criteria*

94. The proposals for the assessment criteria published on 9 May 2011 represent the Department’s initial views on how to assess disabled people and ensure that priority in the benefit goes to those most affected by their impairments. They are an initial draft and the Government is keen to hear views on how they will work and if they can be improved. As such the Department carried out an informal consultation from 9 May to 31 August 2011 to seek views from disabled people and their organisations. Officials have met with around 60 disability organisations to discuss the draft criteria and received more than 100 written responses. The Department is currently looking closely at all the comments that have been received.

95. The Department has also been testing the draft assessment criteria over the summer to ensure that they are accurately and consistently assessing individuals and help understand their likely impact on individuals and the future caseload. The testing involved over 900 individuals taking part in a single face-to-face consultation with a trained healthcare professional employed by a provider on behalf of the Department. Information has been gathered on the volunteers’ circumstances, their impairments and the impact of these on their everyday lives. Volunteers have also been assessed against the published draft of the assessment criteria. The testing is entirely voluntary and will have no impact on individuals’ current or future benefits.

96. The majority of participants in the testing were identified by the Department from existing DLA recipients, to ensure a statistically robust sample. This sample spans the existing rates of DLA and covers individuals with a broad range of health conditions, impairments and severities. The sample is split evenly between individuals with impairments affecting physical and mental function. The Department also worked with a number of disability organisations to identify participants from key groups that it wishes to look more closely at in the testing or who it might be harder for the Department to reach. These include individuals with autistic spectrum disorders, learning disabilities, sensory impairments and Chronic Fatigue Syndrome/Myalgic Encephalopathy (ME). The Department has also assessed a sample of individuals who previously claimed DLA and were not found to be entitled.

#### *Testing—next steps*

97. The assessment testing will be complete by mid-September. Once the Department has considered the results and feedback received from the consultation, it intends to publish a second draft of the assessment criteria. This is likely to be in the autumn. Alongside this the Government also intends to publish the results of the testing and an explanation of how and why the criteria have been refined. The Department will also have had the opportunity to re-consider the participants against the revised criteria and will publish the results

of this at the same time including an indication of the impact upon the existing DLA caseload and future Personal Independence Payment claimants.

98. The Government then intends to carry out a further consultation on the assessment criteria, including draft point scores. Comments from disabled people and their representative organisations on how well the second draft of the criteria work and if they could be improved, will again be welcomed.

#### DELIVERY OF PERSONAL INDEPENDENCE ASSESSMENT

99. The Department is currently in the process of developing the detailed delivery model for Personal Independence Payment, including the assessment process. The proposal is that everybody claiming Personal Independence Payment will undergo an assessment by a trained individual. There have been no decisions taken yet on the backgrounds, skill sets or qualifications that will be required of assessors. While they are likely to be from a healthcare background, they may not be doctors, as other professionals such as occupational therapists may have more appropriate skills. The testing of the draft assessment criteria will help inform decisions on assessor skill sets.

100. Assessments will be delivered by a third party contracted to the Department and commercial activity is planned to begin shortly. This will allow sufficient time for the successful supplier to put in place the resources and infrastructure to support the Personal Independence Payment assessment process from April 2013.

101. As above, the intention is that most individuals will have a face-to-face consultation with the assessor. This will not be a requirement in all cases, however, and some individuals will be assessed on the basis of paper evidence, such as the claim form and supporting evidence provided by the individual or a supporting professional. Where individuals are required to attend a face-to-face consultation, they will be able to bring another person with them, such as family member, friend or advocate. The Department envisages that consultations will take place on official premises or in the claimant's home where necessary. The Department will also ask prospective suppliers to consider options for consultations to be carried out in other locations—for example, GPs surgeries, independent living centres *etc.*

102. The outcome of the assessment will be advice to the Department to support decisions on the appropriate benefit award and award duration. This advice will take account of evidence submitted by the claimant or their representative in addition to the consultation itself. However, final decisions on entitlement to Personal Independence Payment will remain with departmental Decision Makers. They will be able to review and consider all information and evidence provided as part of the claim and scrutinise the advice from the assessors, before making a decision on benefit entitlement.

103. The Department fully recognises the importance of the training, guidance and support given to assessors and Decision Makers and will ensure that this is high quality. The Department will work with disabled people and their representatives on the development of such products.

#### *Harrington review of the Work Capability Assessment*

104. Although the Work Capability Assessment (WCA) and the Personal Independence Payment Assessment will operate very differently, the Department is seeking to learn from the WCA experience, including looking closely at the findings and recommendations made by Professor Malcolm Harrington in his independent reviews of the WCA.<sup>105</sup>

105. Professor Harrington's first review provided the Department with a number of recommendations regarding the WCA which were accepted in full. The Department is currently considering how to reflect recommendations from this review in the end-to-end design of the administration of Personal Independence Payment.

#### *Independent review of the Personal Independence Payment assessment*

106. The Department recognises the need to ensure the new assessment is operating correctly and the value that an independent perspective on this can bring. As such the Welfare Reform Bill includes a requirement for an independent review of the operation of the assessment to be commissioned and for the report on this to be laid before Parliament within three years of the primary legislation coming into force.

107. The independent review will be undertaken by a senior independent figure with a strong background in disability. The Department will look to ensure that disabled people and their organisations can play an active role in supporting the review.

#### *Links to other benefit assessments*

108. The Government is aware that certain individuals will be required to undertake a number of different assessments in order to access a range of benefits and support. These include social care, special educational needs and the WCA. The aims and purpose of these assessments differ significantly and so at this stage the

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<sup>105</sup> Harrington M, 2010, *An Independent Review of the Work Capability Assessment*, TSO.

Government has not sought to join these assessments up. However, the Government recognises that multiple assessments can be burdensome to individuals and may result in the same or similar information being provided on several occasions. The Government will therefore explore opportunities for improving the links between assessments, including the greater sharing of information, to improve the administration of the assessments and the experience of individuals.

#### HOW DISABILITY LIVING ALLOWANCE/PERSONAL INDEPENDENCE PAYMENT SHOULD APPLY TO CHILDREN AND PEOPLE OVER THE STATE PENSION AGE

109. Personal Independence Payment will only apply to individuals of working age (16–64) when it is introduced in April 2013. In its response to the Disability Living Allowance reform consultation, the Government stated that it wished to learn from the experience of introducing a new benefit and reassessing the existing working-age caseload before extending it to children and young people aged under 16 and people aged 65 and over.

##### *Children*

110. The needs of children are different from those of adults and may vary at key stages of development, which is why the Department would need to develop a specific child assessment before Personal Independence Payment could be applied to children. The Government has given a clear commitment that it would consult before making any significant changes to the arrangements for children.

111. The development of the arrangements for children on DLA will also take account of ongoing work across Government. The Department is working with other government departments on a cross-Government participation strategy for improving the participation of young people in education, employment and training. This will consider the role of benefits such as DLA and Personal Independence Payment.

112. The Department for Education's (DfE) Green Paper, *Support and aspiration: A new approach to special educational needs and disability*, published in March 2011, sets out the Government's aspiration to move towards a single assessment process for a child's social care, health and special educational needs, in order to minimise the stress and burden on disabled families who have to go through multiple assessments. The DfE plan to test the approach starting this year and committed in the Green Paper to look at the findings of the pathfinders to explore whether the single assessment process might also be used to support claims for DLA and Personal Independence Payment. The Department is continuing to work with DfE officials to progress work in this area.

##### *Transition of children*

113. The Government recognises that there has been concern about the transition from DLA to Personal Independence Payment when a young person reaches age 16. The Government recognises that this is a very important and sensitive issue and is continuing to work with disability organisations that represent disabled young people to get their views on how this transition can be as smooth as possible. It will not be the case that DLA will simply end at age 16 and individuals will have to seek alternative support. The Department will get in touch with young people and their families before they reach 16, so they know what to expect and what they have to do.

##### *Pensioners*

114. The Welfare Reform Bill provides that people will not be entitled to Personal Independence Payment after they reach age 65 or State Pension age, whichever is higher.

115. The Bill includes a power to make secondary legislation so that individuals below the upper age limit who are in receipt of Personal Independence Payment can continue to receive the benefit beyond that age, provided they meet the eligibility criteria.

116. As part of the normal process of ageing, individuals can expect to experience some health challenges, and this may prevent people from being as active and independent as they would like to be. The Government's intention is that the upper age limit for Personal Independence Payment will ensure that support is targeted to those individuals who face barriers during their working life, and may, therefore, be less able to financially prepare themselves for retirement.

#### REASSESSING EXISTING AWARDS

117. In the three years starting in April 2013 the Government's intention is that all existing Disability Living Allowance claimants of working-age (16–64) will be assessed for Personal Independent Payment. Where individuals satisfy the entitlement criteria for the benefit, they will be transferred from DLA to Personal Independence Payment. Those individuals who are not entitled to Personal Independent Payment, or who choose not to claim it, will not be able to retain their DLA as an alternative.

118. The Department has started to develop processes to support this and as an intrinsic part of this have committed to involving disabled people and their representatives, both at a national and at a grass roots level,

in order to shape its approach. The Personal Independence Payment Implementation Development Group has sought views on potential communication requirements and will also gather views and input on the proposals which underpin the reassessment exercise.

119. The intention is to use customer panels in order to help to build an understanding of their needs and behaviours. This will help to inform the assessment and reassessment processes.

120. The Department propose to publish an outline of the proposed reassessment strategy in advance of Personal Independence Payment clauses being discussed in Lords committee stage of the Welfare Reform Bill.

121. A number of options are being explored for how these cases could be ordered. The Government has given a commitment that the Department would consider beginning the reassessment with a statistically valid sample of cases, perhaps in dedicated locations. The Department would therefore not propose to begin reassessment of these cases until it has successfully completed an initial test of both its systems and processes in a live environment, beginning as soon as would be practicable following the introduction of the new benefit in April 2013.

#### COMMUNICATIONS WITH CLAIMANTS AND THE GENERAL PUBLIC

122. The Government recognises that the communications task in relation to the reform of Disability Living Allowance is challenging; the target audiences are large and complex and their requirements, understanding and behaviours are very diverse.

123. The Department is working with disabled people and their representatives at national and grass-roots level to understand their communication needs and how best to address these. This supports the Department's commitment in Annex 1 of the *Governments response to the consultation on DLA reform* to continue to put the disabled person at the heart of the development of the new benefit and the claim process.

124. Considerable progress has already been made. After the reform of DLA was announced in the Budget in June 2010, the Department began consulting informally with disabled people and disability organisations in advance of the formal consultation exercise. This included developing the new assessment with an independent group of specialists in health, social care and disability, including disabled people.

125. To supplement the formal consultation exercise, Ministers and officials met a large number of disabled people and their representative groups, as well as DWP staff, to discuss reforms and the introduction of Personal Independence Payment.

126. The Government is committed to ensuring that its stakeholders are fully informed and consulted during the development of Personal Independence Payment and that disabled people have a genuine opportunity to influence and shape the detailed design. This is being managed through regular engagement with members of the DWP Customer Representative Group Forum.

127. A Personal Independence Payment Implementation Development Group has been set up to involve customer representatives in the design and delivery arrangements, including how information about the new benefit can be communicated in the most effective way. The first customer representative research groups took place on the 26 and 27 July 2011 and focused on communications for existing DLA claimants and partner information needs, including for example information about the main elements of the new benefit for welfare rights advisors.

128. Customer panels involving disabled people themselves are being put in place. Those involved will be invited to give views on their communication needs throughout key stages of the development of the business process. Detailed customer profiles have been built to understand the characteristics, drivers, channel preferences and health issues of disabled people. These will be used to inform the research fieldwork due to begin in September 2011 which will be facilitated by a specialist external research company. The intention is that learning from these exercises will be used to inform all aspects of communications.

129. Throughout the reassessment process, the Department is committed to ensuring that information will be clear and easy to understand so that claimants know what is going to happen, when it will happen and what they need to do. The Department has already asked for views from the Development Group about reassessment communications and will use this information to help inform the approach. Further insight will also be obtained from the customer research panels.

130. The Department is looking afresh at how it communicates with claimants and their representatives in the pre-claims stage—the period of time during which a claimant finds out about the benefit and decides whether or not to make a claim. Claimants and their representatives will be asked for their views and will be involved in testing communications.

131. The Department will also involve disabled people and their representatives in designing the new claims process. This will be done through the Personal Independence Payment Implementation Development Group and through customer research panels. Information will be tailored wherever possible to reflect individual needs, such as needs of different age-groups, in terms of content and channel preferences and in line with business cost considerations.

132. To ensure that Personal Independence Payment is clearly and effectively communicated the Department is committed to learning from experience. Departmental research reports, insight data and operational analysis are being used to inform communications, particularly from the claimant's point of view and identify potential areas for improvement.

133. When Personal Independence Payment is introduced, the Department will have had considerable experience of managing the move of individuals to a new benefit following the transition of Incapacity Benefit claimants to Employment Support Allowance (ESA). Although ESA and Personal Independence Payment are different benefits with different purposes, the Department will ensure lessons learned from that experience are applied to Personal Independence Payment communications.

134. The Department is also taking Professor Harrington's recommendations into account in the way that Personal Independence Payment communications work. Specific examples include ensuring claimants' are supported through reassessment.

135. The Department is continuing to draw on evidence-based research and insight to inform the strategy and plan activity, it will continue to evolve over time responding to further engagement and feedback from multiple audiences. The results will be monitored against base-lined data and targets to ensure the communications are evaluated.

*8 September 2011*

## DLA REFORM—SUMMARY OF CHANGES—CHANGES MARKED IN ITALICS

	<i>Disability Living Allowance</i>	<i>Personal Independence Payment</i>
Qualifying Period & Prospective Test	Have to have been severely disabled for three months and likely to be for a further six months.	Have to have been severely disabled for <i>six months</i> and likely to be for a further six months.
Principal entitlement rules	Care needs and mobility are the measures used as proxies for extra costs.	<i>Focus is on the impact of a health condition or impairment on the individual's ability to carry out everyday activities, acting as a proxy for extra costs.</i>
Rates and components	Two Components—care and mobility Three care rates and two mobility rates 11 different award outcomes	<i>Two components—Daily Living and Mobility Two rates per component Eight different award outcomes</i>
Assessment process	“Self assessment” claim form with claimant’s own description of their care and mobility needs. Additional medical evidence gathered in around 50% of cases. Medical examination in small minority of cases. Decisions are subjective rather than objective in nature.	<i>Under PIP we intend to have a more objective, evidence based, consistent and transparent claims and assessment process. We will seek to gather more additional evidence in more cases than currently. There will be a stronger focus on information from healthcare professionals involved in supporting individuals. We intend for most individuals to have a face-to-face consultation with an independent trained assessor as part of the assessment process. PIP will not apply to children when it is introduced in 2013. We will use our experience of applying PIP to the working-age population to inform our decisions about children.</i>
Age—Children	Children only able to access mobility rates at certain ages (up to 16th birthday). Additional rules to separate out normal childhood care/mobility needs from those associated with disability. Claims cannot be taken after the age. Entitlement can continue after the age of 65 if already in receipt.	<i>PIP will not apply to children when it is introduced in 2013. We will use our experience of applying PIP to the working-age population to inform our decisions about children.</i>
Age—Over 65s	Claims cannot be taken after the age. Entitlement can continue after the age of 65 if already in receipt.	No change.
Residence and presence/exportability	With some exceptions someone has to be ordinarily resident in Great Britain, not subject to immigration control, present in GB and have been present for an aggregate period of not less than 26 weeks in the previous 52 weeks. Care component exportable. Temporary absence is currently allowed for up to 26 weeks. No consideration currently given to entitlements received from another EEA country.	<i>Habitually resident</i> (to align with other benefits including the proposals for Universal Credit), not subject to immigration control, present in GB and have been present for an aggregate period of not less than 26 weeks in the previous 52 weeks immediately preceding the date on which a claim is made. <i>The 26 out of 52 would be applied on a one off basis and not on a rolling basis.</i> <i>We are proposing reducing the period that temporary absence is allowed to four weeks, to align with ESA.</i> <i>Where another EEA competent state paying an equivalent benefit, PIP is not payable.</i>
Hospital	DLA (both components) ceases to be payable 28 days (84 days for children) after NHS hospital admission. Mobility component can continue to be paid if a Motability agreement in place. Private patients are unaffected by these rules.	No change.



	<i>Disability Living Allowance</i>	<i>Personal Independence Payment</i>
Care Home	The care component ceases to be payable after 28 days of care home residency where the costs of the accommodation are met from public or local funds. The mobility component continues to be paid. People fully funding their placement are unaffected by these rules.	Self-funders continue to receive either component of PIP. Non self-funders lose <i>payability of both the care and mobility components after 28 days.</i>
Award duration/ reviews	Awards can be made for a fixed or indefinite period. Awards are not routinely scrutinised.	<i>Awards will normally be made for a fixed period. Awards will be routinely reviewed.</i>
“Deeming” provisions	Certain conditions are deemed to meet conditions of entitlement despite there being no functional limitation, eg severe mental impairment; severe visual impairment.	<i>There will be no automatic entitlements to PIP, with the exception of the Special Rules for people who are terminally ill.</i>

**Letter from Maria Miller MP, Minister for Disabled People, Department for Work and Pensions to  
Dame Anne Begg MP, Committee Chair**

PERSONAL INDEPENDENCE PAYMENT—ASSESSMENT THRESHOLDS

I am writing to inform you that we have today published on our website—[www.dwp.gov.uk/pip](http://www.dwp.gov.uk/pip)—our initial proposals for the entitlement thresholds for Personal Independence Payment.

In November 2011 we published a second draft of the assessment criteria for Personal Independence Payment, which had been significantly revised and improved following our earlier consultation and engagement with disabled people, their organisations and our assessment development group. This draft included our initial proposals for the weightings associated with the criteria. It did not include any views on the thresholds which will determine entitlement to the rates of the benefit, as we wanted to do further work before finalising these—including hearing initial views on the weightings. This reflects the iterative and co-produced approach we have taken to developing the assessment criteria. We committed to publishing the thresholds before the debate on Personal Independence Payment at Report Stage of the Welfare Reform Bill in the House of Lords and have today met this commitment.

The briefing document sets out the thresholds, includes case studies showing how the assessment criteria are likely to work in practice and provides analysis of the likely impact of the assessment on the benefit caseload, based on the testing we carried out over the summer of 2011. The modelling suggests that the assessment would produce a 2015–16 caseload of 1.7 million receiving Personal Independence Payment. Without introducing the new benefit we would expect the number of 16–64 year olds claiming Disability Living Allowance in 2015–16 to be 2.2 million. The modelling also shows that we are meeting our commitment to target the benefit at those with the greatest need, with a higher proportion likely to receive the highest rates of PIP than would have been the case under DLA.

Today's publication is not the end of the assessment development process and we in particular want to hear further views from disabled people and disability organisations. We have therefore today launched a formal consultation on the second draft of the assessment criteria, including on the weightings and entitlement thresholds. This will run for 15 weeks, ending on 30 April 2012. After this we will carry out further work to refine the criteria, before laying draft regulations before Parliament later this year. I would, of course, welcome the Committee's thoughts as part of this.

I am copying this letter to Committee members, the Committee Clerk and the Speaker's office. I will also place a copy in the House Library.

16 January 2012

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**Written evidence submitted by Professor Roy Sainsbury, Social Policy Research Unit,  
University of York**

INTRODUCTION

1. In 2008 the Social Policy Research Unit (SPRU) was invited to meetings with officials to discuss possibilities for researching the impact of DLA and AA. This followed an insightful paper by Richard Berthoud of the University of Essex (later published in 2009) that recommended a quantitative approach to measuring impact (for example using a new survey or possibly adapting existing surveys). However before such a survey could be devised he recommended qualitative research to explore what types of impact people reported.

2. SPRU undertook such a project, interviewing DLA recipients, AA recipients, parents of child DLA recipients and advisers inside and external to Jobcentre Plus. Findings were published in 2010. (The planned wave of quantitative research was not commissioned however.)

3. I will draw on this research, and other work, in addressing some of the questions in the terms of reference issued by the Committee.

THE NEED FOR REFORM

4. It is interesting that the Committee wants to explore this. The case for reform has been based on the argument that there are weaknesses and deficiencies in the current DLA arrangements. These include:

- Poor understanding of the benefit.
- Lack of routine reassessments of claims.
- Inappropriate assessment criteria for certain impairments.
- The unsustainability of expenditure on DLA.

5. The presentation of the “poor understanding” argument in the Consultation Paper in December 2010, which was reiterated in the recent DWP Impact Assessment (published in October 2011), appears to be conclusive but the evidence is less so. Certainly the studies cited (Thomas and Griffiths 2010 principally) have

evidence that some people have misconceptions about DLA, for example that it cannot be claimed in work, but counter evidence is not cited. In the research carried out by SPRU on the impacts of DLA and AA (Corden *et al* 2010) it was also found that some people thought taking work would affect DLA entitlement, but these tended to be people for whom work was not an imminent possibility. There were also people in the sample who had enquired about DLA and work or had received a “better off” calculation in their attempts to find work. For these people there was a clear understanding that DLA was not affected by working.

6. There does not seem to be any direct evidence that DLA acts as disincentive to work. The nearest evidence is found in Thomas and Griffiths again. It is worth citing in full:

Findings were that there was potentially a “DLA factor,” ... the fact of having a DLA claim, in itself reduces the likelihood of someone saying they would like a job (now or in the future) by more than a third.... Analysis with the money value of DLA awards ... did indicate that the higher the value of award the greater the apparent “disincentive” effect was on work expectations, although again *this is not evidence of a direct causal link* (my emphasis). (p.3)

7. This tentative explanation does indeed seem plausible—that some people could manage on an income that included DLA and therefore were not motivated to find work. However, it is likely that the same effect would be found with PIP. PIP too would provide an additional non means tested income that could dissuade people from looking for work.

8. The argument about DLA lacking routine assessments such that some claimants have remained on benefit for many years (the so-called “DLA for life”) is an important one, but the problem could have been addressed without reforming the benefit. As far as I am aware DWP already has the legislative authority to recall claimants for a reassessment.

9. There has been criticism of the DLA assessment criteria for many years that they do not reflect the lives of people with, for example, sensory impairments, learning difficulties or some mental health conditions. PIP has addressed these concerns.

10. This leaves cost as the final argument for reform. Here the logic is clear—the costs of DLA have increased (to £12.6 billion in 2011–12) and the numbers claiming have risen (from 2.5 million to 3.2 million in the last eight years according to the DWP October Impact Assessment). The Select Committee itself raises in its Terms of Reference the question of why the caseload has increased.

11. I would draw the Committee’s attention to a DWP report published in August 2011 entitled, *Disability living allowance: Growth in Caseload*. This report is cited by a number of organisations in their websites and in submissions to the Select Committee posted on websites. It revises the estimate of the rise in caseload downwards from the 30% level cited in the DLA consultation document in December 2010. Unfortunately it seems that the report is no longer available on the DWP website. The address:

[http://statistics.dwp.gov.uk/asd/asd1/adhoc\\_analysis/2011/DLA\\_Growth\\_in\\_Caseload\\_FINAL.pdf](http://statistics.dwp.gov.uk/asd/asd1/adhoc_analysis/2011/DLA_Growth_in_Caseload_FINAL.pdf) brings up only a “Page Not Found” response.

If the Committee could get hold of this report it would inform their consideration of the case for reform.

12. One other factor that should be looked at in relation to the rise in DLA caseload is the take up rate for the benefit. In 1998 DWP analysis of the Family Resources Survey estimated take up of the care component of DLA at between 30–50% and take up of the mobility component at 50–70% (these figures were reported in the Select Committee on Social Security report on its inquiry into Disability Living Allowance). The policy intention at the time was deliberately to increase take up. At the time an increase in caseload was looked on as a positive development rather than, as now, a problem.

#### THE IMPLICATIONS OF A REDUCTION IN EXPENDITURE

13. The answer to the problem of escalating benefit costs is a familiar one: redraw the eligibility criteria more tightly in order to reduce the number of successful claims. PIP does this but it is not clear what the effect of the changes will be. The Impact Assessment is not entirely clear but seems to cite benefit savings of over £2 billion so there is presumably the expectation of a significant reduction in the flow of new claimants and a reduction in the stock of DLA claimants as they are reassessed for PIP.

#### THE IMPACT OF DLA

14. The Committee might be interested in the findings of the research project conducted by SPRU for DWP referred to above. At the time (2008) policy makers wanted evidence on how DLA (and AA) affected people’s lives. Put simply, they wanted to know whether the benefit was doing any good or whether there was a case for rethinking how the state helps people with the costs of disabilities. An important context to remember was that the Wanless review of the costs of social care had been published in which the possibility was raised of subsuming the DLA and AA budgets within local authorities’ social care budgets.

15. In conducting the research it was important to distinguish between how people spend their DLA and the impact of receiving it. Berthoud’s contribution is useful here by identifying the different types of ways in which DLA can offset the “costs of disability”.

- *DLA can support additional expenditure* on specific items, such as personal care, household services, heating, food, medical expenses, or transport.
- *DLA can improve specific outcomes*, ie reflecting that spending *per se* does not guarantee a desirable outcome (for example a person could spend more of fuel but still not be warm enough).
- *Generalised compensation for additional expenditure*, ie referring to the practice of some disabled people of cutting back on some items of expenditure in order to pay for the additional costs generated by disability. So, for example, someone might cut back on food or clothing in order to pay for additional heating costs. Hence, DLA and AA can be seen as compensating people for those additional costs.
- *Countering the effects of being disabled*, ie in ways not directly associated with the additional costs of disability, such as paying for activities that enhance social participation.

16. The SPRU research found evidence of a wide range of impacts, some linked with spending others not. DLA helped people to meet the actual expenses of:

- personal care;
- transport;
- food;
- fuel;
- home maintenance, including cleaning, gardening and small jobs;
- health care, medical equipment and supplies;
- telephones and computers;
- social activities; and
- giving presents, gifts and “treating”.

17. But other uses included:

- helping practical money management;
- enabling access to other kinds of support (through “passporting”);
- providing a safety net, especially during financial transitions;
- preventing, or helping management of, debts;
- enabling people to live at home;
- keeping people part of society;
- acknowledging people’s condition; and
- enabling paid work.

18. Later research analysing the English Longitudinal Study of Ageing (ELSA) and the FRS Disability Follow up Survey (Mackinnon *et al*, 2011) found some, but few, significant differences between DLA recipients and non recipients in spending and some measures of social inclusion.

19. What emerges from the research on the impact of DLA is that the benefit enhances the lives of people in a wide variety of ways beyond paying for what is normally thought of as “social care”. In the SPRU research findings showed that most direct personal care and support of elderly and disabled people living in the community was unpaid, and provided by partners, adult children and other family members. For many DLA and AA recipients, managing daily living also depended on finding solutions and working out ways of doing things which reduced the amount of direct help they needed, and enabled them to maintain control and some independence.

20. What has not been attempted to date is analysis of the wider societal impact of DLA, particularly how it affects spending on health and care services. There is evidence that people’s health and well being are positively influenced by the receipt of DLA so such an analysis would potentially be very informative.

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