Proposal to replace DLA with Personal Independence Payment

Written Evidence

As of 12 December 2011
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<td>1</td>
<td>Robert Leonard Brown</td>
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<td>Kevin Kelleher</td>
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<td>Martin Wilsher</td>
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<td>Lisa Egan</td>
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<td>Centre for Mental Health, Hafal, Mental Health Foundation, Mind, Rethink Mental Illness, the Royal College of Psychiatrists and the Scottish Association for Mental Health</td>
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<td>6</td>
<td>The Children’s Society</td>
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<td>Trades Union Congress</td>
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<td>National Centre for Independent Living</td>
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<td>Mencap</td>
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<td>Citizens Advice</td>
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<td>Disability Benefits Consortium</td>
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<td>Carers UK</td>
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<td>Inclusion London</td>
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<td>Sofie Rosemary Haidon</td>
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<td>16</td>
<td>Oxfordshire Welfare Rights</td>
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<td>17</td>
<td>Muscular Dystrophy Campaign</td>
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<td>18</td>
<td>Citizens Advice Scotland</td>
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<td>19</td>
<td>North West Mental Health and Welfare Rights Group</td>
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<td>Ecas</td>
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<td>21</td>
<td>MS Society</td>
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<td>Margery M Browning</td>
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<td>23</td>
<td>Richmond Citizens Advice Bureau Service</td>
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<td>24</td>
<td>Papworth Trust</td>
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<td>25</td>
<td>Motor Neurone Disease Association</td>
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<td>26</td>
<td>Every Disabled Child Matters</td>
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<td>27</td>
<td>Mental Health Advocacy Project (West Lothian)</td>
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<td>CLIC Sargent</td>
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<td>Law Centre Northern Ireland</td>
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<td>Association of British Insurers</td>
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<td>31</td>
<td>National AIDS Trust</td>
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<td>32</td>
<td>Community Mental Health Team (Kentish Town)</td>
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<td>33</td>
<td>Local Government Association Social Security Advisers Group</td>
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<td>34</td>
<td>Scottish Disability Equality Forum</td>
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<td>35</td>
<td>RNIB, Action for Blind People, Guide Dogs, Sense, Visionary, National Blind Children’s Society, SeeAbility and the National Federation of the Blind</td>
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<td>36</td>
<td>The National Deaf Children’s Society</td>
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<td>37</td>
<td>Headway - the brain injury association</td>
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<td>38</td>
<td>ECDP</td>
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<td>39</td>
<td>Scope</td>
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<td>40</td>
<td>Yare Valley &amp; District Citizens Advice Bureau</td>
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<td>41</td>
<td>Macmillan Cancer Support</td>
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<td>42</td>
<td>ENABLE Scotland</td>
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<td>43</td>
<td>The National Autistic Society</td>
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<td>44</td>
<td>Danka Gordon</td>
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45  Sense
46  Contact a Family
47  South Lanarkshire Council Money Matters Advice Service
48  Scottish Campaign on Welfare Reform
49  Motability
50  David Gillon
51  London Borough of Lambeth
52  Professor Steve Fothergill, Centre for Regional Economic and Social Research, Sheffield Hallam University
53  Department for Work and Pensions
54  Convention of Scottish Local Authorities
55  Arthur Rucker
56  Professor Roy Sainsbury, Social Policy Research Unit, University of York
Written evidence submitted on behalf of Mr Robert Leonard Brown (PIP 1)

My husband was awarded full care and mobility for life in 1993. I have the award letter which clearly says for life. How can the government reneg on this? Also, my husband was put through many tests by private doctors employed by the DWP. It was decided my husband’s condition would not improve. Indeed, since 1993 he has had MRI scans which reveal prolapsed discs in the spine and neck. He has also developed hereditary diabetes since hitting late fifties. Because he also has fibromyalgia doctors will not risk operating on his spine or neck. He also has colitis and other underlying problems and is constantly at one consultant or another. To look at him you would think he looks ok but he lives on 28 tablets a day. He would not object to being retested. His medical records show their own story. But he and I feel that it is this government's evil intent to change the criteria which means many troubles will no longer be counted and leave many disabled worse off than they already are. This is morally repugnant to attack the sick and needy. This way is beneath contempt but of course we have no unions behind us which make us an easy target. First soften the public up with lies in the sun saying we are all scroungers and illegally let others use are mobility vehicles for their own use and they can get away with this attack on disabled people. You may get away with it and put the disabled movement back years but god will pay you back do someone a bad deed and it will always come back to haunt. To date apart from benefits my husband has never asked social services for anything. He even took out a loan with Abbey National to get a council home fit to live in. Ironically, the last payment is due 1/7/2013. If this policy goes through many will be forced into grinding poverty and this will cost the tax payer in many having to go into care or blocking up hospital beds. Believe me if this Pip goes through it will haunt future governments and cause havoc among the disabled community.
I submit for the committee consideration the following information and analysis regarding the above list Call for Evidence.

1. The UK currently have a population of about 62 million people and submit a breakdown as at August 2010:

<table>
<thead>
<tr>
<th>August 2010</th>
<th>No of People</th>
<th>No of People</th>
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</thead>
<tbody>
<tr>
<td>Population</td>
<td>61,838,154</td>
<td>Population 61,838,154</td>
</tr>
<tr>
<td>Bereavement Benefit</td>
<td>-64,700</td>
<td>DLA paid too 3,204,280</td>
</tr>
<tr>
<td>Carers Allowance</td>
<td>-1,002,600</td>
<td>AA paid too 1,791,920</td>
</tr>
<tr>
<td>Carers Allowance</td>
<td>Children</td>
<td>-12,553,000</td>
</tr>
<tr>
<td>Carers Allowance</td>
<td>Children - Disabled</td>
<td>-770,000</td>
</tr>
<tr>
<td>Carers Allowance</td>
<td>ESA</td>
<td>-563,980</td>
</tr>
<tr>
<td>Carers Allowance</td>
<td>Incapacity Benefits</td>
<td>-1,851,010</td>
</tr>
<tr>
<td>Carers Allowance</td>
<td>Job Seeker Allowance</td>
<td>-1,349,710</td>
</tr>
<tr>
<td>Carers Allowance</td>
<td>State Pension</td>
<td>-12,561,260</td>
</tr>
<tr>
<td>Carers Allowance</td>
<td>Widows Benefit</td>
<td>-49,110</td>
</tr>
<tr>
<td>Carers Allowance</td>
<td>Working Population</td>
<td></td>
</tr>
<tr>
<td>Carers Allowance</td>
<td>Working Population F/Time</td>
<td>-21,124,000</td>
</tr>
<tr>
<td>Carers Allowance</td>
<td>Working Population P/time</td>
<td>-7,910,000</td>
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<td></td>
<td></td>
<td>2,038,784</td>
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</table>

2. People could apply for PIP meet the criteria, receive confirmation of entitlement but when an Income is over a certain value, payment is not made (like that of Carers Allowance).
3. The UK estimates that the UK that about 10 million people are disabled and about 3.2 million claim DLA.

4. HM Government suggests a cap of £26,000 on benefits, yet the Dilnot Commission suggest costs could range from £35-£100K, compare this with a weeks cost of residential care £400-800 per week, this level of benefit is cost affective, provides choice and independence at home instead of state alternative care. (I have included my submission to the Human Rights committee on Independent Living for Disabled People).

5. The current Independent Living Fund programme support about 20,500 (was 21,500) people in the UK, this is about 3-5% the total UK receipt DLA are High Care (790,680 – August 2010) which is need to meet the requirements of the ILF fund. On average the ILF funds equal about £50,000 per person, like DLA there are various rates.

<table>
<thead>
<tr>
<th>Description</th>
<th>Total</th>
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<tbody>
<tr>
<td>Aids related disease</td>
<td>110</td>
</tr>
<tr>
<td>Arthritis (osteo-rheumatoid-still's dis)</td>
<td>658</td>
</tr>
<tr>
<td>Blood disease (inc leukaemia)</td>
<td>3</td>
</tr>
<tr>
<td>Brain damage (inc head injury)</td>
<td>961</td>
</tr>
<tr>
<td>Cancers-tumours</td>
<td>70</td>
</tr>
<tr>
<td>Cardio-vascular (inc heart disease)</td>
<td>80</td>
</tr>
<tr>
<td>Cerebral Palsy</td>
<td>2981</td>
</tr>
<tr>
<td>Cerebro-vascular (inc stroke)</td>
<td>747</td>
</tr>
<tr>
<td>Dementia (inc Alzheimers)</td>
<td>86</td>
</tr>
<tr>
<td>Down's syndrome</td>
<td>1045</td>
</tr>
<tr>
<td>Epilepsy</td>
<td>435</td>
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<tr>
<td>Friedreich's ataxia</td>
<td>173</td>
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<tr>
<td>Huntington's Disease</td>
<td>119</td>
</tr>
<tr>
<td>Hydrocephalus</td>
<td>55</td>
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<tr>
<td>Condition</td>
<td>Count</td>
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<td>------------------------------------------------</td>
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<tr>
<td>Lung or respiratory disease (inc asthma)</td>
<td>61</td>
</tr>
<tr>
<td>Mental illness</td>
<td>123</td>
</tr>
<tr>
<td>Motor Neurone Disease</td>
<td>84</td>
</tr>
<tr>
<td>Multiple Sclerosis</td>
<td>2642</td>
</tr>
<tr>
<td>Muscular Dystrophy or Atrophy</td>
<td>534</td>
</tr>
<tr>
<td>Osteoporosis</td>
<td>55</td>
</tr>
<tr>
<td>Other</td>
<td>1577</td>
</tr>
<tr>
<td>Parkinson's disease</td>
<td>123</td>
</tr>
<tr>
<td>Physical malformation limbs-Thalidomide</td>
<td>30</td>
</tr>
<tr>
<td>Polio damage</td>
<td>104</td>
</tr>
<tr>
<td>Severe learning disability</td>
<td>6099</td>
</tr>
<tr>
<td>Spina bifida</td>
<td>341</td>
</tr>
<tr>
<td>Spinal injury</td>
<td>1314</td>
</tr>
<tr>
<td>(blank)</td>
<td>169</td>
</tr>
<tr>
<td>Grand Total</td>
<td>20610</td>
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6. HM Government could cap PIP on an income level of £150-250,000 per year (currently DLA is not means tested)
7. This enquiry should take into consideration the UK’s ageing population and in the increase in the number of people likely to be registered disabled (accessing benefits or not).
8. This enquiry should take into the findings and recommendation of the Dilnot Commission, Independent Living for disabled people and other relevant Parliament committee’s relevant to the reform to welfare support.
9. This enquiry should take into consideration the amounts paid listed at Rightsnet
10. This enquiry should take into consideration the current level of those in receipt of benefits
11. This enquiry should look at those accessing DLA/PIP will most likely have a severe medical condition or terminal illness which should be taken in to consideration. From my experience is protracted, costly through administration and appeals instead of being up front and supportive. Further time, administration and costs are incurred seeking medical advice.
12. HM Government spend £100million pounds per year on the administration of ATOS surveying claimants etc., this money could be better resourced and used.
13. This enquire could look changing the payment schedule from arrears to advanced as currently payments are made either 1 or 4 weeks in arrears but you must at the time have some form to credit to meet the costs incurred until the DLA/PIP payment is received. DS1500 should also be paid in advance.
14. DLA/PIP is a passport to access additional support services and this should not change.
15. The DWP may wish to consolidate it structure and payment through Income Support instead of the current system in use.
16. And finally I ask to provide additional information that arises before that stated closing date.
Written evidence submitted by Martin Wilsher (PIP 3)

Summary of points addressed.

1. 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. 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. Whether automatic entitlement should apply to people with some conditions or impairments and whether some people should receive awards for indefinite periods.

4. The implications of a six month qualifying period.

5. The extent to which PIP will act as a gateway to other benefits, including Carers Allowance and the Motorbility Scheme.

6. 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. 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.

8. The steps DWP needs to take to ensure that its reform proposals are clearly and effectively communicated to claimants and the general public.


   1. 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.
My response.

[Paragraph 1 A.

I believe the DLA case load has increased for two reasons.

since 1992 medical advances have allowed those who have disabilities or medical conditions who meet the criteria to qualify for DLA to survive where previously they may not have done so. And:

the affect of those of pension age being able to continue to claim DLA after reaching 65. if those who reached 65, and were claiming DLA, had to migrate to attendance allowance, the DLA case load would fall to those of working age and pre sixteen. I believe these two factors are the reasons why the DLA caseload has increased over the last 19 years.

Paragraph 1 B.

Speaking of the review and decision making process, here is my experience. I, having recently gone through a review to update my DLA due to a an increase in needs due to disability, feel the current review system to be stacked against the claimant. Though I sent all relevant evidence showing my sight loss, the first application for a higher rate of benefit was refused. I found I had to send a blow by blow account of my day, and how my sight loss affected me. There was no guidance in the pack to explain this was what was needed. Thanks to welfare rights, I was able to get help with understanding what the review body needed from me. If the reviewers want a day by day diary breakdown of difficulties, then why not state that in the review form? Also, I do not agree with the government when they state there is no method for reviewing those claiming DLA. All the government need do is send out a review form to those who they deem need reviewing, as they do for income related, and out of work benefits at present. Constant reviewing of a claimant where their situation is unlikely to change, such as those who are blind with no hope of regaining sight, is cost ineffective and likely to place the claimant under huge stress, and lead to appeals, due to incorrect decisions, such as with the current situation regarding tests for eligibility for Esa.

2. 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.

My Response:

Paragraph 2 A.

This is quite simple to answer, lower levels of DLA help those with mild or moderate needs to pay for adaptations and access services to avoid their condition becoming critical, the increase in need to critical or substantial means more money would have to be spent. The impact of only two levels of PIP would mean those with mild needs would not qualify, meaning those needs might become
moderate or severe, negating the savings to be had by paying a little in a payment for mild conditions, to maybe stop their escalation into moderate or severe. I am worried about the wording, “those with the greatest needs,” how is that defined? I am blind, I get middle rate care and high rate mobility of DLA at the moment, as my needs are seen as moderate in care and severe in mobility as the world is not set up with blind people in mind. Care for me includes paying for my computer to read my post, paying for pre prepared or processed foods to enable me to cook, as I can’t cook fresh ingredients such as potatoes etc, the DLA pays for specialist labelling equipment for me to label foods. Without this technology I am stranded, and would become more dependant on human help. My mobility needs are recognised by the high rate of mobility component of DLA, as I have issues navigating unfamiliar areas and need help on those areas due to my sight loss. PIP should not throw out all the recognition of disability and it’s impact on life gained under DLA. If the slate is wiped clean, as it were, disabled people would become more dependant, not more independent.

Paragraph 2. B.DLA pays for aids and adaptations, and those aids and adaptations need updating from time to time, such as new software for computers, replacement of canes, payment for taxis in unfamiliar areas etc.

3. Whether automatic entitlement should apply to people with some conditions or impairments and whether some people should receive awards for indefinite periods.

My response:

Paragraph 3A.

Automatic entitlement should carry on where the medical evidence shows that the person has a significant loss of function, such as those who are deaf blind, and those who are totally blind, paraplegic, quadriplegic etc, where common knowledge would suggest that the world is not accessible for them. There should be a set of criteria set, that if met, should trigger automatic entitlement, be that by medical evidence, test or certificate from a consultant.

4. The implications of a six month qualifying period.

My Response:

Paragraph 4A.

I believe six months is too long to wait for PIP. Six months without the means to purchase help or care would result in strain on families, financial hardship to claimants, and their families, if any, and lack of dignity and care for the disabled person claiming the benefit. PIP should be able to be claimed right away in the case of traumatic disability, such as permanent disability due to accident, being
born with a disability, or where a consultant has stated categorically that there is no chance of recovery or improvement of the disability. I am blind, I will always remain so unless they make eye transplants a reality, so it can be said, and has been said, that my award of DLA is indefinite, as there is no likelihood of my condition improving. If I lost my sight today, and had to cope for six months with no recognition under PIP from the state of my disability, I do not know what I’d do, or how I’d cope for those six months that I had to wait, while knowing myself I had no way of coping, getting help to live, while waiting for the benefit waiting time to elapse. This proposed six month waiting time is disgusting on so many levels, and is being designed in just to make things easier for civil servants. We are not talking about people who can change disability, we are talking about those who have life altering situations, which the majority of the population never have to face. In short, a six month waiting time is inhumane, indeed, the three month waiting time currently in place for DLA is a disgrace I feel.

5. The extent to which PIP will act as a gateway to other benefits, including Carers Allowance and the Motorbility Scheme.

My Response:

Paragraph 5 A.

I think PIP should continue to be a gateway benefit as DLA is now.

6. 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.

My Response:

Paragraph 6. A.

I will only talk about how aids and adaptations should be taken into account. My view is they should not. I am blind, I use a computer to read my post, to communicate with people also. This use of DLA to fund a computer is seen, however obliquely, as there is no specific communication portion of DLA, as replacing a human who would read my post to me and write my letters, as well as give me privacy. Under Pip, because I have a computer, I will be seen as less disabled, which is untrue, for if the computer becomes faulty, and I have no money to replace it, I become more dependant without the computer. Using aids and adaptations which are paid for by DLA at present, to assess the person’s eligibility for PIP against the disabled person seems very wrong to me. At the moment, there is no alternative ways of getting a computer for blind people to communicate. Yes there are educational grants etc, but a computer is not just used for education, it’s used for communication outside education. Until the government puts in place funding for basic mobility, communication and other aids to living for disabled people, using the aids against them, which they purchase with DLA, or would purchase with Pip, is ridiculous and discriminatory.
Personal independence payment would be a misnamed benefit, for it would foster dependency, as disabled people would feel they could not make strides to make their lives more independent, in case they lose their entitlement. In short, I could not do without the means to pay for my computer or my taxi rides to unfamiliar areas, or my processed foods, which are more expensive, but enable me to cook independently, as they have cooking instructions on them, which I can follow, or my talking microwave.

7. 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.

My Response:

Paragraph 7 A.

The work capability assessment, as it currently stands, is not a good model for deciding who qualifies for PIP. The assessment method is too simplistic. For instance, how will the assessment, the draft criteria released in May 2011, assess how a blind person needs help. Why sweep away everything that has been learnt about various disabilities and pretended disability is not disabling any more? The world has not become more accessible, as a whole, it might have in London, but we don’t all live in London. Taking my position, as a blind person, I do not have talking busses, I don’t have access to talking cash machines, I can’t see when my clothes are dirty. This will not change in 2013, just because the benefit says I am less disabled. Also, if the assessors for the new benefit know the stated aim of the assessment is to save money, we will end up with a situation as regards PIP, that is current with the work capability assessment, with all the inherent issues surrounding.

8. The steps DWP needs to take to ensure that its reform proposals are clearly and effectively communicated to claimants and the general public.

My Response:

Paragraph 8 A.I think the government first needs to decide what it wants. It has been shown recently that the government do not know what they want from PIP. They talk of a 20 percent reduction in pip expenditure, and of massive fraud, but fraud is only 0.8 percent, according to DWP figures for May June 2011. 0.8 percent is hardly massive fraud. Independence costs money when the world does not consider a disabled person’s right to access. A cut of 20 [percent would mean that 19.2 percent of the caseload would be genuine claimants. This is flying in the face of the government’s stated aim of independence for disabled people.

My Response:

Paragraph 9 A. Transitional arrangements should be as now, pay DLA at current rates while being assessed for pip, then migrate to new assessed rate once proper and thorough evidence based objective assessment has been carried out.
Summary

[1] I am a disabled person currently in receipt of DLA. The change from DLA to PIP will have a hugely negative impact on me. In this report I explain my impairment and how it affects me, why I currently get DLA; and how I will fare under the PIP assessment process. I am not asking you to investigate any individual case; I am merely presenting to you evidence of how one vulnerable person will be harmed. My case is not unique and should not be considered as such, I am merely one example of many of this country’s disabled population who will be adversely affected if the PIP proposals are pushed through in their current form.

Introduction to the submitter

[2] I currently receive DLA at the Higher Rate for Mobility (HRM) and Middle Rate for Care (MRC). The evidence I wish to present is in relation to the element of your inquiry looking at the implications of the reduction in spending and impact on those in need.

[3] I have Osteogenesis Imperfecta¹ and have had somewhere in the region of 50-55 fractures in my 32 years, most recently 2 ½ weeks ago when I bent down and heard one of my ribs snap. Activities during which I’ve broken bones include walking⁴, sleeping⁵, and eating⁶. I get MRC because of my need for constant supervision during my waking hours due to my bones breaking. Osteogenesis also results in my joints dislocating easily⁷.

[4] I get HRM because I’m virtually unable to walk. I can walk a very short distance but only very slowly and with extreme pain and difficulty. My osteogenesis means that a good many of my joints have been shattered so have extremely limited movement. The rest of my joints are held in place by tendons and ligaments of such poor quality that my 4kg cat can dislocate my knee by sitting on it. Because my tendons and ligaments don’t do a good job of holding me up I fall over very easily, which is really not very safe in someone with brittle bones. Between the pain, the difficulty, the slowness and the danger involved in walking I’d be pretty much housebound without a wheelchair. I couldn’t even walk as far as the bus stop at the top of my street (and it’s a short street) before my knees had swollen up so much that I couldn’t bend them for the rest of the day. My consultant orthopaedic surgeon has told me to walk less than the little bit I already do around the house because I’m causing permanent damage to my joints. I’m wearing them out and I’m only 32.

Factual information: How my condition affects me and how that is likely to result in me losing my benefit based on a reading of the draft PIP criteria

[5] Having read the draft PIP criteria published in May 2010⁸ it looks like I will not get a penny in future.

[6] The mobility component will no longer be assessed on your ability to "walk"; it will be assessed on your ability to "mobilise". The difference being that they’ll consider your ability to get around using a wheelchair. And if you can get around using a manual wheelchair your benefit will be denied.
The majority of the time I am perfectly capable of propelling my manual wheelchair. It had to be custom built because my deformed arms\textsuperscript{vii} mean I couldn’t reach the wheels adequately in a wheelchair off-the-rack; but I can propel it for many miles without difficulty ordinarily. Obviously sometimes I do have difficulties, like when I’ve recently dislocated my shoulder or when I’ve just broken a rib, but I don’t believe it’s frequent enough for me to be deemed incapable of pushing a manual wheelchair 50m for the purpose of the assessment.

[7] Losing my mobility component will mean I lose my Motability car. This will result in my becoming unable to go shopping (because I just can’t carry that much stuff on my lap in my wheelchair). I know some HRM claimants who are unable to drive put their money towards online supermarket deliveries. This will not be an option for me because without my HRM I will be unable to afford the delivery charges! Of course I’ll also be denied almost all social activities without my car: I won’t be able to visit my frail, elderly, widowed, father and I won’t be able to visit friends due to the largely inaccessible nature of public transport. Despite the fact that humans are social beings I won’t end up dying as the result of becoming unable to participate in almost all social activities. However I haven’t yet worked out a plan for being able to get out and procure sustenance. I live alone: I have no partner, no children, and no siblings. My mother is dead and my full-time wheelchair-using father lives 100 miles away. As a result of my current social exclusion even with a car I already have no local friends who could shop for me\textsuperscript{viii}, so losing my car will put me in great danger.

[8] Then there’s the Care component of DLA becoming the Daily Living component of PIP. According to the draft criteria it will be assessed on:

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

[9] I notice "needs supervision for safety reasons" has gone. This means I will be losing that along with my Mobility component. It’s not just going to impact on me and other people like me who injure easily due to physical conditions like brittle bones, it’ll affect a huge number of people who currently get DLA due to mental health problems or conditions like epilepsy. The safety consequences of this move for so many people will be devastating.

[10] I currently have an indefinite award for DLA: Osteogenesis imperfecta doesn’t get better. Re-assessing me and other people with my condition on an annual/every 3 years/every 5 years/etc. basis would be a complete waste of government money to pay for the assessment and the associated administration. I’m aware that under the current plans I’m going to be losing my benefit but other people with more severe OI than me (people than cannot self-propel a manual wheelchair and/or people that need help with preparing food, showering or getting dressed) will receive PIP.
The re-assessment process will be costly for the government and will not save any money by finding that people have improved, because that improvement will never happen.

Recommendations for action

[11] I’m aware that the government is pushing through these reforms claiming the “most vulnerable” will still be protected and using tables and statistics to show why saving 20% on the DLA bill will be workable. I have written this report to put a human face to the plans and to show you how a “vulnerable” person will be affected when the new criteria is applied. I strongly recommend that the government abandons this plan driven purely by cost-cutting ideals because the impact on so many disabled individuals will be so grave.

[12] I recommend considering the impact on the nation’s motor industry when the overwhelming majority of the UK’s wheelchair users will be having their Mobility component stripped, which will result in them losing Motability car.

[13] Finally I would recommend not regularly re-assessing people with incurable conditions. It will not save the government any money because you won’t find any people that have improved. In fact it would cost money for the assessment process and you’ll be inflicting unnecessary stress on the disabled individual involved.

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1 http://www.oif.org/site/PageServer?pagename=fastfacts
2 December 2008 I tore a tendon out of a metatarsal which pulled the tip of the bone off with it. This injury was the result of simply walking normally.
3 In the early hours of 01/01/2000 I slept in an awkward position. I got woken up by blinding pain at about 4am. The awkward sleeping position had crushed not just one but several vertebrae
4 As a child I caught my forearm on the edge of the table while eating dinner. This light tap caused my forearm to snap (I only have one forearm bone now where the radius and ulna have been broken so many times they’ve fused together).
5 Examples include dislocating my right shoulder by bending down to pick up a towel, having my left knee dislocated by someone walking into me and dislocating my left thumb in my sleep.
7 from being broken repeatedly during my childhood
8 You may be thinking “but she gets MRC for constant supervision and she has no-one looking after her!” Remember that currently the criteria for DLA are assessed on your need for help, not whether or not you’re actually getting that help.

September 2011
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.1

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.2. 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”.3

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1 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).
2 HM Treasury (2010) Budget 2010
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. 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.

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%.

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.

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.

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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.8

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.9 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.

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. 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.8

9 http://www.demos.co.uk/files/Counting_the_Cost_-_web.pdf?1292598960
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.

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 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 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 affect 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, e.g. when a person has an acute episode of psychosis and is admitted to hospital for a 3 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.

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 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 emphasis 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. ¹⁰ Many of these stories have included quotes from the Government.

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

[http://www.thesun.co.uk/sol/homepage/news/3383419/150m-payouts-for-an-allergy.html](http://www.thesun.co.uk/sol/homepage/news/3383419/150m-payouts-for-an-allergy.html)
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
- Informing and supporting thousands of people on a daily basis

A fundamental part of Mind’s work is provided though 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 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 3000 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).

September 2011
Written evidence submitted by the Children’s Society (PIP 6)

Introduction

The Children’s Society supports nearly 50,000 children and young people every year through our specialist services and children’s centres. We believe in achieving a better childhood for every child but have a particular focus on vulnerable children who have nowhere else to turn. We seek to give a voice to children and young people and influence policy and practice so they have a better chance in life.

As a leading children’s charity committed to making childhood better for all children in the UK we welcome this opportunity to contribute to this inquiry. Our submission will focus on how the proposed transitions to PIP will impact on disabled children and disabled young people moving onto PIP at the age of 16.

1. Summary

1.1. Key messages:

- Disability Living Allowance (DLA) is an effective way to support some of the most disadvantaged families in the UK and has a significant and beneficial impact on families’ lives. Any reform of DLA should be based on a thorough analysis of what works and what does not work in the current system. The needs and experiences of disabled children and young people themselves should inform DLA reform to ensure that their future life chances are not affected negatively.

- All children and young people who have additional needs associated with a disability should have these needs met. Decisions about what support they require should be based on an assessment of their needs and not on the availability of resources.

- The welfare system should be brought in line with other legislation relating to children by treating all under 18 year olds as children rather than adults. Currently only under 16 year olds are considered children in the welfare system.

- Disabled young people and their families should be offered additional support during transition to the adult benefit system.

- The mobility component of DLA/PIP for children and young people in residential schools should be retained to allow children to participate in leisure and community-based activities and to keep in contact with family and friends. Removal of the mobility component is likely to have a negative impact on their well being and future life chances.

- The new assessment for qualifying for the PIP should be based on both the social and medical needs of disabled people.

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The current qualifying period of three months should be maintained.

2. **Experiences of disabled children and their families applying for the Disability Living Allowance**

2.1 The research available regarding DLA demonstrates that it is an effective way to support some of the most disadvantaged families in the UK and that it has a significant and beneficial impact on families’ lives. It is used to pay for care and support, enabling disabled people to stay with their families. It also contributes to transport needs enabling disabled people to access leisure activities, maintain their social contacts and be more independent.

2.2 The importance of DLA for disabled children and young people, as well as the experiences of young people applying for this benefit in their own right at the age of 16, is not well researched. This should be further examined.

2.3 Research demonstrates that the complexity of the benefit system prevents many families from receiving benefits to which their child is entitled. Decision making can be arbitrary and 54% of negative decisions are overturned on appeals. A number of problems has been identified which prevent families from receiving their full benefit entitlement. The barriers include: information not being shared with families about which benefits they are entitled to, the complexity of the necessary forms, decision makers not being aware or having little understanding of the range of conditions/disabilities and/or not listening to parents’ suggestion about who might be most suitable to provide additional evidence.

2.4 There is little research into the take up rates for DLA and into the number of children under the age of 16 and young people from the age of 16 who are entitled to it and who are actually claiming this benefit. The Work and Pensions Select Committee has previously emphasised the need to ensure that DLA reaches more disabled people.

2.5 We believe that any reform of the benefit system should be based on thorough analysis of what works and what does not work in the current system and that the needs and experiences of disabled children must inform the DLA reforms to ensure that their future life chances are not affected negatively.

3. **Impact of transition to DLA/PIP at 16**

3.1 We are concerned that the changes to DLA are driven by the need to make savings of 20%, rather than by ensuring appropriate levels of support for disabled children and...
young people. Consequently, around 40,410 disabled young people aged between 16-24 may lose this essential benefit designed to meet additional needs associated with disability. This contradicts the Government’s commitment to eradicate child poverty and to improve the life chances of disabled children and young people.

3.2. The process for introducing the PIP lacks detail and is not based on an in-depth impact analysis, and a proper analysis of the risks to those who will be affected by these changes. We know that the changes will affect disabled young people at a very important transition time in their development when foundations are laid for their future.

3.3. Overall the research highlights the anxiety and uncertainty experienced, both by the young person and his/her family, when a young person turns 16 and has to reapply for DLA. There is also anecdotal evidence to suggest that at the age of 16 young people are not always getting DLA at the same rate as earlier. And although there is a provision allowing families to claim DLA for their child until the child turns 19 if the child is assessed as not being able to take care of his/her finances, they still have to reapply for DLA at around the age of 16.

3.4. Transition workers, who support disabled young people and their families through the transition process, also perceive welfare benefits for young people as a complex issue, particularly for young people living in supported or residential accommodation.

3.5. The Government’s response to the consultation on DLA recognises that ‘the needs of children are very different to those of adults’. Nevertheless the current benefit system is not aligned with other legislation and guidance in relation to children – as outlined below – and disabled children from the age of 16 are treated as adults. We believe this is not right.

- The United Nation’s Convention on the Rights of the Child (UNCRC), which was ratified by the UK in 1991, defines a child as ‘every human being below the age of eighteen years’.
- This is reflected in the safeguarding legislation and also in some benefit legislation, for example, for the purposes of child benefit childhood continues until the child is 19 or even 20 in some circumstances.

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8 See: [www.ablemagazine.co.uk/exclusive-interview-maria-miller-mp-on-the-dla-consultation/](http://www.ablemagazine.co.uk/exclusive-interview-maria-miller-mp-on-the-dla-consultation/)
10 the Minister for Disabled People in December shortly after the consultation on DLA was launched: “we are looking at saving 20% of the Disability Living Allowance expenditure in line with the Chancellor’s commitment.”
11 An estimate based on the DWP statistics Disability Living Allowance all entitled cases November 2010. It shows that there 202,050 disabled young people 16-24 claiming DLA.
The recently published Green Paper ‘Support and aspiration: A new approach to special educational needs and disability’ recognised that disabled children and their families need more support than other families and that transition to adulthood for disabled young people is a more complex process that requires additional planning and joint working across the range of services. To this end, it proposes to introduce a single ‘Education, Health and Care Plan’ which will identify support needed from birth until the age of 25.

The Education and Skills Act 2008 increased the minimum age at which young people in England can leave learning, thus requiring them to continue in education or training to the age of 17 from 2013 and to the age of 18 from 2015. This is a fundamental change and also means that young people will not be able earn a wage from the age of 16, as before.

3.6. We believe that changes to DLA should not be driven by the need to save resources alone and that all disabled children and young people should have their needs met to ensure that they have the same life chances as other children. We believe that to achieve this the welfare system should be brought in line with the legislation relating to children and should recognise particular vulnerability of children at transition points.

4. Retaining of the mobility component of DLA/PIP for children and young people in residential schools and residential care

4.1. The proposals to remove the mobility component for people in residential care is based on assumption that there is an overlap in funding from care and education packages and that young people living in residential care have all of their transport needs provided for by the package of support purchased by the local authority. We know that this is not the case.

4.2 Transport provided by an education or care provider is often limited, with no extra provision for spending time with family and friends or extra curricular or leisure activities. Each young person is an individual with his/her own interests. Just because an individual young person lives in residential care does not necessarily mean he/she wants to live his/her life as a ‘group’. We know from our practice that young people use the mobility component of DLA to access activities outside their residential placements, to attend community groups, visit places of interest or to meet with friends and family, to participate in everyday activities just as their peers who do not live in residential placements. These individual needs are not met by residential placement providers, and very often there are no alternatives to access these activities. This is for a variety of reasons, including residential placements may be in rural areas where there is not enough public transport, or young people may needing to be accompanied and a lack of staff making it possible only for group outings to take place.

4.3 Critically, the DLA mobility component also enables family members to visit children and take them out during term time or for the child’s transport in the holidays. Family
carers also often use the DLA mobility component to pay for adaptations to vehicles. Removing the mobility element could also mean the loss of access to adapted cars and powered wheelchairs through Motability schemes.

4.5 We have calculated the cost of keeping the mobility component for the around 10,000 under 18 year olds and the around 13,000 under 24 year olds in residential care. Our analysis found that it would cost just £10 million annually to allow continued payments for all those under 18 and only an additional £5 million (so £15 million in total) annually to extend this to those under the age of 24. The continued investment of these relatively small amounts of money, constituting an extremely small proportion of the overall benefit bill, would make a substantial difference to these particularly vulnerable children’s lives.

4.6 We believe that the removal of the mobility element of DLA would have a negative impact on the well being of disabled young people, their mental health and sense of choice and control over their lives. It could also constitute a breach of their rights, in particular under UNCRC Article 31 which recognises the right of the child to rest and leisure, to engage in play and recreational activities appropriate to the age of the child and to participate freely in cultural life and the arts, and the right of the child to participate fully in cultural and artistic life. It could also be in contravention of equality legislation by not allowing the equality of opportunity as well as against the government’s commitment to protect the most vulnerable against the cuts.

5. PIP draft assessment criteria
The government published the initial draft criteria for the PIP assessment in May 2011 and is currently consulting on it. We are concerned that the draft assessment criteria are based on a medical, rather than social, model of disability. The questions are narrower than those for the DLA assessment which asked about things individuals would like to do and the support needed to achieve these things. The DLA form specifically included a reference to a reasonable amount of social activities. From our practice with disabled young people, we know that the issue of friendship and the ability to get out and about is particularly important for their well being.

6. Qualifying period
We are concerned that a qualifying period of 6 months as proposed under PIP will leave many young people over 16 and their families without support for a considerably longer period at a vulnerable and stressful time. This will particularly impact on those who face sudden onset conditions such as a cancer diagnosis, a stroke or a serious accident. We are also concerned that if the 6 month qualifying period applies to disabled children under 16, those born with specific complex needs and impairments will not receive vital support for an extended period. Moreover, this extension of the qualifying period is not in line with the Green Paper ‘Support and aspiration: A new approach to special educational needs and disability’ that emphasises ensuring disabled children get the support they need as quickly as possible.

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^14 Modelling is based on DWP Benefit Caseload National Statistics November 2010, and Disability Alliance estimates of number of people in residential care receiving Mobility component of DLA.
Introduction

1. This document presents the TUC’s submission to the Work and Pensions Committee’s inquiry into the government’s plan to replace Disability Living Allowance (DLA) with Personal Independence Payment (PIP).

2. The TUC is the voice of Britain at work. With 58 affiliated unions representing more than six million working people from all industries and occupations, we campaign for a fair deal at work and for social justice at home and abroad. We negotiate in Europe, and at home build links with political parties, business, local communities and wider society.

3. The TUC appreciates the importance of the Committee’s inquiry and we are grateful for this opportunity to contribute to its work.

Summary

- The TUC agrees that DLA eligibility rules can be confusing and that the claim form is very complicated, but this does not justify a reduction in the scope and generosity of the benefit.

- Disabled people are more likely than non-disabled people to face poverty and restricted life chances. If there is a weakness in the current system of provision, it is that it is not generous enough, not that it is too generous.

- Contrary to many newspaper stories, fraud and malingering are rare among DLA claimants.

- The TUC does not agree that the benefit should be focused on people facing barriers to independence and integration that are more serious. Even disabled people with moderate or minor impairments face extra costs. We are opposed to only having two rates of the proposed ‘daily living’ component of PIP.

- We do not believe that there is an overlap in provision between the DWP, the NHS and local authorities. The TUC therefore opposes the exclusion of people in residential care homes from the mobility component.

Confusion and complexity

4. The TUC agrees with the government that some aspects of DLA should be reformed. The long forms faced by claimants and the uncertainty about entitlement are drawbacks and people with sensory or communications impairments can face particularly significant obstacles. In 2007, DWP research reported that claiming DLA without the support of a professional adviser can be very difficult:

   the application forms are found by customers to be lengthy and complicated, with a key issue appearing to be the need to typify or quantify everyday experiences, when it is common for different disabilities and illnesses to result in variable impacts. This is particularly difficult for those with sensory or mental health problems, who largely find the forms inapplicable. For those who do not have professional help, this is notably problematic.

5. We also consider that DLA reflects assumptions that were common twenty years ago, basing entitlement too frequently on impairment. This is not in accordance with the social model of disability. Other things being equal, we would support measures to address these problems.
Why is there going to be a new test of eligibility?

6. This does not mean, however, that it is now time to replace DLA with a benefit that covers fewer people or provides a lower level of benefit. PIP seems to have been designed primarily with a view to cutting spending - the test of eligibility was planned before the benefit itself. The “objective test” was announced in the June Budget, where it was described as a test for DLA, not a new benefit.

7. At that point, the only indication that the government had any objective other than cutting spending was an aside in the Chancellor’s Budget speech about “significantly improving incentives to work” (which seemed to betray ignorance of the fact that DLA is not an out-of-work benefit). The commitment to making savings was, however, crystal clear, and Mr Osborne put this proposal in the context of concerns that “the costs have quadrupled in real terms to over £11 billion, making it one of the largest items of government spending.” Furthermore, the detailed budget documents described the objective of the reform as “a 20 per cent reduction in caseload and expenditure once fully rolled out.”

Disabled people and poverty

8. Disabled people are particularly likely to face poverty. The Households Below Average Income Statistics show that, in 2009/10, people who live in households that include a disabled person are more likely to be poor than other people:

<table>
<thead>
<tr>
<th>Status</th>
<th>Proportion Poor (%)</th>
<th>Before Housing Costs</th>
<th>After Housing Costs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Those living in families where no-one is disabled</td>
<td>16</td>
<td>21</td>
<td></td>
</tr>
<tr>
<td>Those living in families where someone is disabled</td>
<td>21</td>
<td>25</td>
<td></td>
</tr>
<tr>
<td>No disabled adult, 1 or more disabled child</td>
<td>14</td>
<td>21</td>
<td></td>
</tr>
<tr>
<td>1 or more disabled adult, no disabled child</td>
<td>21</td>
<td>24</td>
<td></td>
</tr>
<tr>
<td>1 or more disabled adult, 1 or more disabled child</td>
<td>26</td>
<td>38</td>
<td></td>
</tr>
</tbody>
</table>

9. If we confine ourselves to families where someone is disabled, we can see the tremendous difference that disability benefits like DLA make:

<table>
<thead>
<tr>
<th>Status</th>
<th>Proportion Poor (%)</th>
<th>Before Housing Costs</th>
<th>After Housing Costs</th>
</tr>
</thead>
<tbody>
<tr>
<td>In receipt of disability benefits</td>
<td>12</td>
<td>16</td>
<td></td>
</tr>
<tr>
<td>Not in receipt of disability benefits</td>
<td>25</td>
<td>29</td>
<td></td>
</tr>
</tbody>
</table>

The need for DLA

10. Disabled people repeatedly insist on how important DLA is for them. As a DWP research report noted:

DLA recipients of working age were unanimous in expressing views that DLA made a big difference to them. All the adult DLA recipients in our study group were people who had been living on low out-of-work incomes for some time. Typical comments were that DLA ‘enables me to live’. Some said, without DLA, they would not be able to pay their bills, or get the help they needed. Parents of child recipients who were living on low incomes said their children’s lives would be adversely affected, for example, spending less on items needed for their disabled child, such as extra lessons. However, the more generally reported effect would be reduction in living standards for the whole family.

11. The problem with DLA is not that too many people receive too much, but that it does not meet these costs in full. In 1998, a (currently unavailable) DSS report found that only 40 to 60 per cent of
those eligible for DLA actually received it.\footnote{1} More recently, Berthoud and Hancock looked at DLA/AA recipients and concluded that whilst these benefits did significantly boost claimants’ incomes, they left them “little or no better off than other Income Support and pension credit claimants.” While this suggests that these benefits are (just about) adequate, it is worth bearing in mind that they also found that “the weekly amounts involved are not enough to pay for the care theoretically required.”

12. Tibble’s literature survey points out that “Most studies conclude that disabled people’s needs are not fully met through services, and the cost of private provision to meet needs is not fully covered by extra costs benefits.” Corden et al’s research into how people use their DLA and AA found that they felt that the most important use of the benefit was in maintaining independence and control. In line with this, DLA and AA were being spent on:

- Personal care;
- Transport;
- Food;
- Fuel;
- Home maintenance;
- Health;
- Telephones and computers;
- Social activities;
- Giving presents, gifts and ‘treating’.

13. Disabled people would be likely to spend less on all these activities without these benefits. All of them are likely to involve extra costs for some disabled people.

**Fraud**

14. DLA fraud is comparatively rare. DWP statistics published in June showed that overpayments due to fraud accounted for a smaller proportion of spending on DLA than on Income Support, Jobseeker's Allowance, Pension Credit, Housing Benefit, Carer’s Allowance or Council Tax Benefit. Fraud accounted for just 0.5 per cent of DLA spending. All fraud is wrong and any amount is too much but focusing on this issue as if it were one of the most important features of the system is unbalanced.

15. Berthoud’s research into Trends in the Employment of Disabled People in Britain is a very useful corrective to the common complaint that the number of disabled people “can’t” have risen in recent years and that increasing numbers must be due to the availability of benefits like DLA. Using General Household Survey data for the numbers who say they have a “limiting long-term illness” his calculations show that the prevalence of disability “rose gradually between the mid-1970s and the mid-1990s, before falling gradually over the following ten years.” What is more, “most of the growth in the prevalence of limiting long-standing illness, and most of the rise in the disability employment penalty, has affected people at the more severe, rather than the less severe, end of the spectrum. This suggests that the underlying trend is a true one, not simply associated with people’s reports of, or responses to, trivial conditions.”

‘Focusing’ support
16. The proposed structure of PIP effectively abolishes the lower rate of the DLA care component (in Feb 2011, 890,000 people who received DLA received the care component at the lower rate, 28 per cent of the total.) When Disability Living Allowance was created two pre-existing benefits were merged and a new lower rate for the care element was created. This was a particularly important innovation, extending coverage to a large group of people with less severe impairments and health conditions who nonetheless had significant care needs that up till then were left unmet.

17. It is a great shame that the current proposals – the most progressive and positive social security measure introduced by the last Conservative government – reverse this reform. Even people with mild or moderate impairments face extra disability-related costs; twenty-five years ago the groundbreaking OPCS disability surveys revealed that even people in the lowest severity category faced an average of £3 a week extra costs. These averages hid many people paying a lot more and when PSI re-analysed the OPCS data they found:

- 30,000 people paying more than £50 a week;
- 70,000 people paying £30-£50 a week;
- 190,000 people paying £20-£30 a week;
- 840,000 people paying £10-£20 a week.

18. In his literature survey for the Department, Tibble noted that researchers have come to differing conclusions about the relationship between severity of impairment and additional costs. Those who have found that there is a relationship have also found that, while costs may be lower at the less severe end of the spectrum, they do still exist.

Conclusion

19. In response to protests at changes to disability benefits by the Hardest Hit campaign, the Minister for Disabled People said

*It is only right that support should be targeted at those disabled people who face the greatest challenges to leading independent lives.*

In a sense, of course, this is undeniable - once the decision to cut benefit spending is accepted this approach is unavoidable. But it does underline our central claim: that a desire to reduce spending is the key reason for these proposals. They are not based on an analysis of the needs of disabled people.

References


September 2011
Internal Application for Vacancy pays band A – E
(Please read before completing the attached application form)

As an internal applicant, you are clearly instructed as to which parts of the form you need to complete. **These sections are marked with an *.” You are not required to complete all sections.

I. Unless you will be away from your department for a period of time, please complete section 2 with your **internal HoC/ PICT address**.

II. As an internal candidate you are asked to obtain a manager’s assessment (pages 7-8) from your line manager to be included with your application.

III. When you have completed your internal application form, it should be forwarded to the campaign manager within the recruitment team whose contact details are on the front of the application form. Your completed form can either be emailed or sent in the internal post.

IV. You must ensure your application form and manager’s assessment is received by the central recruitment team by the closing date. This is shown on the front of the application form.

V. Your Departmental Head of HR will be advised of your application to assist the administration process.

A Manager’s Assessment form must be completed as part of your application form. This form will only be used for internal recruitment. (Pages 7-8 of the application form)

I. The assessment form will be based solely on performance assessment of your current role and your manager will be asked to provide evidence of how you meet the top three criteria for the job.

II. It is important that you advise your line manager that you are applying for a particular vacancy so that they are aware that they will receive the assessment form from you and that they must complete it in good time so you may meet the closing date.

III. The form, when completed by your line manager will then need to be signed by your countersigning officer.

IV. It is your responsibility to ensure that your manager has completed the assessment form and you must include it with your completed application.

Please return your application form with completed Manager’s Assessment by the closing date to the campaign manager Katy Warner preferably by email to warnerkj@parliament.uk or to HR Services Directorate, 3rd floor, 7 Millbank.

If you have any queries with regard to this vacancy or require further information, please contact the above campaign manager.

**Please Note: Completion of Probation** - Permanent and fixed term employees of the House of Commons Service and PICT are eligible to apply for internal vacancies, provided you have successfully **completed your probationary period**.

---

**Applicant to complete (Please tick the box to confirm)**

I confirm I have passed my 9 month probation

---

1 of 10 October 2011
House of Commons
Internal Application for Employment

In Confidence
Section A - Personal Details

Type/use black ink to complete this form as it will be photocopied. Complete questions 1-9 in block capitals.

Post applied for: Senior Executive Officer B1 Closing Date: 19/12/11

Ref Number: 111059

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<thead>
<tr>
<th>1. Surname</th>
<th>Title</th>
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Forename(s)

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<th>2. Address for Correspondence</th>
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<td>(please give HoC address unless away from office)</td>
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Postcode* Telephone (Home)*

Email address* (Work)*

3. Nationality (Mobile)

4. Do you currently have the right to work in the United Kingdom?
   Yes No

If you are not a British citizen or a citizen of another country in the European Economic Area you will need to apply to the UK Border Agency before you can take up employment in the UK.

If you have the right to work in the UK for a limited period of time (e.g. Visa or Work Permit), when does it expire? (You should note that your right to work in the UK may not be transferable between different jobs).

5. Where did you see this job advertised?

6. Data protection statement

We are collecting the information in each section of this form to help us assess your job application. It will be used for our recruitment and selection procedure. It will be seen by members of recruitment boards, HR staff, other managers in the House of Commons and recruitment agency staff. If you are employed by the House of Commons some of the information will be transferred to the HR Services database and to managers in your department. This information will be kept until you are aged 77 (for pension purposes). If you are not selected for this post the information may be passed onto another recruitment board, but if not required will be destroyed after one year. If you have any concerns about the collection or use of this information you should contact the Senior HR Manager – Recruitment Services who is our Data Protection Representative on behalf of the Clerk of the House.
Section B: Skills and Experience *

7. Employment history *
Please give details of all employment that you have undertaken in the past 10 years in date order starting with the most recent. Please use a continuation sheet if necessary. Dates should be continuous. Any gaps should be detailed at question 9.

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<thead>
<tr>
<th>Present or most recent post</th>
<th>From (mm/yy)</th>
<th>To (mm/yy)</th>
<th>Position held and main responsibilities</th>
<th>Reason for leaving</th>
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<td>Name of Company:</td>
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<th>From (mm/yy)</th>
<th>To (mm/yy)</th>
<th>Position held and main responsibilities</th>
<th>Reason for leaving</th>
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<tr>
<th>Previous post</th>
<th>From (mm/yy)</th>
<th>To (mm/yy)</th>
<th>Position held and main responsibilities</th>
<th>Reason for leaving</th>
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<tr>
<td>Name of Company:</td>
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8. Education and qualifications *
Starting with the most recent, give details of all qualifications you hold that are listed as essential or desirable for this post. Please include relevant professional or vocational qualifications or graduate and post-graduate educational qualifications. Where secondary educational qualifications (e.g. A-levels or GCSEs) are not essential for the post, only list them if you have no higher level educational qualifications. If selected for interview you will be asked to provide original certificates for all qualifications listed as essential for this post.

<table>
<thead>
<tr>
<th>Level of award e.g. degree, diploma, A-level</th>
<th>Subject</th>
<th>Grade or class awarded</th>
<th>Date awarded</th>
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</table>
9. Give details of any time not already accounted for in the last 10 years

<table>
<thead>
<tr>
<th>Dates</th>
<th>Reason</th>
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Tick this box if you have used a continuation sheet □

10. Provide details of any dates you cannot attend test or interview. We will try to avoid these dates if you are shortlisted but cannot guarantee to do so. *

11. Experience and skills*

The following criteria have been identified as being essential or desirable for this post. You should provide one or two specific examples of past achievement and/ or training that demonstrate how you meet each criterion. Please do not generalise (e.g. “My usual task is to...” or “I would normally...”) or significantly exceed 250 words per section as either could disadvantage your application.

Excellent oral communication and interpersonal skills with experience of exercising tact, discretion and diplomacy, and the capability to deal convincingly with people at all levels, including Members of Parliament.

Good written communication skills including the ability to draft papers for management group, take accurate notes of meeting and proofread effectively.
| Ability to work using own initiative and proven experience of decision making |
| Ability to give authoritative advice competently and convincingly |
12. Is there anything else you wish to tell us that you have not had the opportunity of doing elsewhere on this application form?

13. Declaration  I declare that: *

- The details on this application for employment and achievement record are correct to the best of my knowledge and belief. I understand that any false statement or withholding of information asked for on this form may be sufficient cause for rejection or, if employed, dismissal.

- I have read the data protection statement above and agree that information from this exercise can be stored and processed in the manner described in that statement.

- I consent to the House of Commons obtaining information from the referees I have provided about performance and conduct at work, and absence from work.

Signed:  

Date:  

6 of 10  

October 2011
14. Manager's Assessment Form

Please could you complete the form below outlining some examples of the candidate’s performance in the specified areas. Your assessment should be based on your knowledge of the candidate in the role in which you have managed them. Please be aware that you should provide what you feel to be a fair and accurate assessment, and that this information will be shared with the candidate.

Once completed, this form should be forwarded to the countersigning officer.

<table>
<thead>
<tr>
<th>Your Name</th>
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<tbody>
<tr>
<td>Your Job Title</td>
<td></td>
</tr>
<tr>
<td>Name of Candidate</td>
<td></td>
</tr>
<tr>
<td>Candidate’s Current Job Title</td>
<td></td>
</tr>
<tr>
<td>Candidate’s Current Pay Band</td>
<td></td>
</tr>
<tr>
<td>How long have you managed this person?</td>
<td></td>
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</table>

Please provide examples/evidence of achievements and behaviours against the areas outlined below:

Excellent oral communication and interpersonal skills with experience of exercising tact, discretion and diplomacy, and the capability to deal convincingly with people at all levels, including Members of Parliament.

Good written communication skills including the ability to draft papers for management group, take accurate notes of meeting and proofread effectively

Highly organised with the ability to set targets and determine priorities, whilst working under pressure with a methodical approach and the flexibility to respond to rapidly changing circumstances
**How closely does the candidate meet the essential requirements of the role for which they are applying?**

Please carefully read the enclosed job description and briefly outline your view on the candidate’s suitability for the role. Your feedback will be considered alongside all of the other evidence collected by the panel during the selection process.

<table>
<thead>
<tr>
<th>Good Match</th>
<th>Close Match</th>
<th>Partial Match</th>
<th>Not suitable</th>
<th>Unable to Comment</th>
</tr>
</thead>
</table>

Please tick the box that best matches your assessment of the candidate’s suitability for the post. This box should reflect the above feedback.

Is the candidate currently undergoing any formal performance, disciplinary or absence management process?  Yes/No

If this application represents a promotion for the candidate, please tick the box that best matches your assessment of the candidate’s suitability for promotion to the relevant pay band. This box should reflect the above feedback. Please refer to the Pay Band Guidance [http://intranet.parliament.uk/Documents/intranet/finances/assets/pay-band-guidance-2009.pdf](http://intranet.parliament.uk/Documents/intranet/finances/assets/pay-band-guidance-2009.pdf)

<table>
<thead>
<tr>
<th>Exceptionally fitted</th>
<th>Fitted</th>
<th>Not Fitted</th>
<th>Unable to Comment</th>
</tr>
</thead>
</table>

If your assessment of promotability is “not fitted” or “unable to comment” please explain why below.

---

**I declare that the information I have provided above is accurate to the best of my knowledge.**

Signed
Reporting Officer

Date

Signed
Countersigning Officer

Date

I confirm that the countersigning officer has seen and agreed this manager’s assessment form

(If this form is to be emailed, line manager please tick box as confirmation)
The House of Commons Service recognises and values the diversity of its staff. It is committed to promoting equality of opportunity for all and developing working practices which will allow every member of staff to contribute their best. We are committed to ensuring fairness and equal access to all employees whatever their gender, nationality, ethnicity, disability or age.

To help us with this, please answer questions 1 to 6. This information will be treated in the strictest confidence.

1. Name: ........................................... Campaign reference number: ..................

2. Are you: Male ☐ Female ☐

3. Do you consider yourself to have a disability? Yes ☐ No ☐

4. Do you consider yourself:
   A) British or Mixed British ☐
   B) English ☐
   C) Irish ☐
   D) Scottish ☐
   E) Welsh ☐
   F) Other (specify below if you wish) ☐

5. Do you consider yourself:
   OR Mixed Ethnic Background
   A) Bangladeshi ☐
   B) Indian ☐
   C) Pakistani ☐
   D) Other Asian background (specify below if you wish) ☐
   I) Asian and White ☐
   J) Black African and White ☐
   K) Black Caribbean and White ☐
   L) Any other mixed ethnic background (specify below if you wish) ☐

   OR Black
   E) African ☐
   F) Caribbean ☐
   G) Other black background (specify below if you wish) ☐
   M) Any White Background (Specify below if you wish) ☐

   OR Chinese
   H) Any Chinese background (specify below if you wish) ☐

6. Age last birthday........................

PLEASE CHECK THAT YOU HAVE ANSWERED QUESTIONS 1, 2, 3, 4, 5 and 6.
PLEASE SEPARATE THIS FORM FROM YOUR APPLICATION AND SEND IT IN A SEALED ENVELOPE MARKED ‘CONFIDENTIAL’ TO:

The Diversity Manager, Department of HR & Change, 3rd Floor, 7 Millbank
Written evidence submitted by Mencap (PIP 9)

About Mencap
Mencap is the UK’s leading learning disability charity, working with people with a learning disability, their families and carers. We want a world where people with a learning disability are valued equally, listened to and included. We want everyone to have the opportunity to achieve the things they want from life.

About learning disability
A learning disability is caused by the way the brain develops before, during or shortly after birth. It is always life-long and affects someone’s intellectual and social development. It used to be called mental handicap but this term is outdated and offensive. Learning disability is NOT a mental illness. The term learning difficulty is often incorrectly used interchangeably with learning disability.

Executive Summary

Mencap has been contacted by many people with a learning disability and their families expressing concern about the proposals to reform Disability Living Allowance (DLA) and replace it with the new Personal Independence Payment (PIP). They describe DLA as a “vital benefit” for people with a learning disability and have expressed their concerns about loss of the benefit and the negative impact this would have on the quality of life of many people with a learning disability.

Following the Government’s announcement about the reform of DLA, Mencap launched a survey in order to find out more about how people with a learning disability spend their DLA. In total 996 people with a learning disability and their families completed the survey and the findings were published in a report produced by Mencap, DLA: why it matters in February 2011. We have used some of the findings from this report to support points raised in this inquiry.

The key points included in this submission are:

- We do not support the overall objective of a ‘reduction target’ of 20% as set out in the Budget report in June 2010. Although the Government has stated its commitment to supporting disabled people, we are concerned that the approach being taken is primarily concerned with reducing costs.

- The numbers of disabled people to be affected by the proposed changes still remains unclear. The DWP have not published any modelling on the likely numbers of people who will lose DLA / PIP support as a result of the proposed changes.

- A focus on those with the “greatest need” suggests that people with ‘lower level’ need – but who still face additional costs associated with their disability – will leave

many people without the support they need. This goes against the Government’s commitment to PIP as a continued “extra cost” benefit.

- The broader impact of the loss or reduction of DLA support is not being fully considered by the DWP. The people accessing the lowest rates of DLA are often unlikely to be able to access support elsewhere and cuts to these groups could lead to unsustainable pressure on social care or NHS budgets, meaning people’s needs could remain unmet elsewhere. We believe greater analysis of these potential knock on costs to government is required.

- The removal of the mobility component of DLA for people living in residential care is based on a flawed argument and will leave thousands of disabled people trapped at home. This policy undermines the government’s commitment to promoting social justice for disabled people.

Mencap is a member of the Disability Benefit’s Consortium (DBC) and a leading member of the Every Disabled Child Matters (EDCM) campaign. We support both the DBC’s and EDCM’s response to this consultation.

Response

The need for DLA reform

While there have been some positive proposals about simplification of the benefit (DLA to PIP), reducing bureaucracy and a better understanding of the extra costs faced by disabled people, there remain significant concerns and a general lack of clarity on a number of key issues.

In particular, Mencap remains concerned that reform of DLA is ultimately being driven by a cut to the budget and will deny many people with a learning disability the support they need. Given that the Government has described the replacement of DLA with PIP as an “opportunity to improve the support for disabled people and better enable them to lead full, active and independent lives” it seems completely inappropriate to introduce an arbitrary target of 20% ‘expenditure and caseload’ reduction to limit the number of claimants receiving PIP. It may well be that improvements to the system will result in savings to government, but this should not be the driver for reform. There is no evidence that some disabled people no longer need DLA – therefore, the government needs to be much clearer on where they believe the current abuse or wastage is within the system or risk cutting support for people in genuine need. While we absolutely support any action to tackle benefit fraud, ensuring those who have genuine need are supported, a DWP report in 2005 suggested a figure of only about 0.5% overpayment of DLA due to fraud.

2 Fraud, error and other incorrectness in Disability Living Allowance, DWP, 2005.
If reform of the system is genuinely about ensuring people who need support are getting it and that the new PIP remains "an extra costs benefit" to support disabled people, it is essential that there is careful consideration of the original purpose of DLA and a more thorough understanding of how it supports a range of disabled people.

The implications of a reduction in expenditure

DLA has been described by the Department for Work and Pensions as providing: “a financial contribution towards the generality of extra costs experienced by… disabled people as a direct result of their disabilities… [DLA was] introduced as a policy response to the evidence that disabled people and their families suffered greater disadvantage and poverty than their non-disabled peers and preceded the opening up of the disability rights framework, including the introduction of measures to tackle discrimination against disabled people.”

It is an “extra costs” benefit and is paid not on the basis of a medical diagnosis, but to compensate disabled people for the extra costs incurred by the effect their condition has on their ability to get around or look after themselves. DLA also recognises the additional costs incurred by families with disabled children, and by disabled parents (as a consequence of the combination of both their disability and their parental responsibilities). It is vital that the Government ensure that any changes to DLA are not based on meeting arbitrary targets, but on better supporting disabled people and their families to overcome the additional costs and barriers that can drive them into poverty. DLA plays a major role in addressing disability poverty - once extra costs are taken into account poverty levels jump from 23% to 40-60% - the implications of withdrawing it are therefore significant for long term life chances and future demand on other state services.

The impact of disability-related costs on disabled people’s standards of living is well known. A review of research by the DWP concluded that “all studies conducted to date have concluded that there are extra costs incurred by disability”. This report further states that: “Most studies conclude that disabled people’s needs are not fully met through services, and the cost of private provision to meet needs is not fully covered by extra costs benefits.” Quantifying the extra costs of disability is complex. As a recent Demos report highlights, there is no single factor that can be used that acts as an “adequate proxy for total disability cost”. The report notes a number of characteristics that can affect the cost of an individual’s disability, including suitability type and location of accommodation, reliance on public transport, level of informal support from family and friends, employment status and so on.

In a survey undertaken by Mencap on DLA usage by people with a learning disability, Mencap asked respondents to explain how they use their DLA in order to support the extra costs associated with their disability. The findings included:

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3 Attendance Allowance, Disability Living Allowance and Carer’s Allowance, Retrospective equality impact assessment, September 2010
4 Review of the existing research on the extra costs of disability, 2005, DWP working paper 21
5 Counting the Cost, Claudia Wood & Eugene Grant, Demos, 2010
higher laundry costs and higher spend on cleaning products;
higher than average heating, electricity and phone bills due to medical, physical and personal care needs;
specialist food as a result of dietary requirements or purchasing of ready meals due to difficulty with cooking;
higher transport costs;
paying for help around the home (e.g. cooking meals, sorting bills) and with shopping;
help to access leisure activities and support with transport.

71% of respondents said that DLA made a positive difference to their life.

Focus on 'greatest need'

It remains unclear what the Government means by focusing on those with the “greatest need” whilst still committing to PIP remaining an “extra costs” benefit and in the context of a 20% reduction target. We believe that such a focus will exclude many disabled people with lower level need but who still face additional costs associated with their disability or condition. This concern is compounded by the introduction of the two rates (as opposed to the existing three) of the equivalent care component in PIP – the daily living component. The Disability Alliance estimates that over 750,000 disabled people could lose support as a result of a 20% expenditure cut based on the assumption that low rate care support will be abolished.

Tightening social care eligibility criteria mean that many people with a learning disability who currently claim DLA receive no support from their local social services department – a situation that is worsening. Since the Comprehensive Spending Review 2010 local authorities have been seeking more ways to make savings, many choosing to reduce the number of people getting care and support by tightening eligibility criteria. Mencap has evidence that 11.12% of local authorities have tightened their eligibility criteria since the recent round of budget setting.

Mencap’s survey DLA: why it matters found that a significant 84% of respondents spent some or all of their DLA on paying for care and support. This was across all rates of DLA.

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6 See: http://www.disabilityalliance.org/r68.doc
7 In 2007/08, 74% of local authorities set eligibility at ‘substantial’ or ‘critical’ only – from Cutting the cake fairly, CSCI review of eligibility criteria for social care, Commission for Social Care Inspection, 2008. This figure is expected to rise according to the Care Quality Commission and Coalition on Charging with many councils already consulting on tightening eligibility and increasing costs of care.
8 In a study undertaken by Mencap, using Freedom of Information requests and research into council budgets, we found that 17 out of the 151 local authorities now operate at a higher eligibility banding after the most recent round of budget setting. Financial pressures were cited as a reason for this decision. From these, Mencap identified many local authorities who introduced sub-categories to the eligibility bandings, by way of reducing the number of people who get care without going up to the next eligibility banding, for example, providing care to greater substantial and above. (Mencap: Study of Eligibility Criteria, August 2011)
and therefore also included people who were receiving some social services but told us that they needed to use their DLA as a “top up” to this support.

Further consideration must be given to the potential impact of a reduction in DLA on already stretched social care budgets. Many people who are not deemed ‘disabled enough’ will be hit twice, potentially losing both their DLA and not meeting the threshold for social care. It is misleading to suggest, as the DLA reform consultation document does, that DLA is “part of a wider range of support and services available to disabled people… including in the form of services or direct payments from Local Authorities to meet social care needs”. In reality, large numbers of disabled people are not eligible for other services. For these people, DLA is an absolute lifeline.

The extent to which overlaps in funding exist

The Government proposes to remove the mobility component of DLA / PIP for people living in residential care. This is a regressive step which will deny 80,000 people their independence and limit their participation in community life. The Government has stated that the proposal is based on an overlap in local authority funding (as one of a number of other justifications they have given for the proposal). We do not support this view and believe it is based on a flawed understanding of how the mobility component of DLA is used by disabled people.

While the Government has announced a review of the situation, this is an internal review only. There are no opportunities for contributions by disabled people and the findings of which are not due to be published. The Low Review was therefore set up in July 2011 in order to provide a public review to complement the Government’s own internal review.

The report DLA: Sorting the facts from the fiction – supported by a range of disability organisations, care home providers and endorsed by ADASS – demonstrates the need for and usage of DLA mobility which is above and beyond what is provided for by either social care or NHS funding. The same applies to the care component of DLA. As noted earlier, we know that many people with a learning disability use their DLA as a top up or – if they are not eligible for social care services at all – to fully pay for varying levels and types of care and support. This is a legitimate use of DLA. Its removal from these individuals would likely lead to unsustainable pressure on social care and/or NHS budgets, and therefore unmet need.

http://www.publications.parliament.uk/pa/ld201011/ldhansrd/text/101209w0001.htm#1012094200076

December 2010

DLA mobility: sorting the facts from the fiction. See: http://www.mencap.org.uk/node/6193

http://lowreview.org.uk/
However, additionally, DLA is intended to support a wide range of ‘extra costs’ associated with having a disability which are not met elsewhere – for example, higher utilities or transport costs.

**Should the automatic entitlement apply to people with some conditions**

Currently, people who are “severely mentally impaired” or have “severe behavioural problems which require help day and night” will automatically receive the higher rate mobility component of DLA. While we can sympathise with an approach which is personalised and recognises that the same condition or disability type will impact on people in quite different ways, we would take a pragmatic approach on this. Similarly to the Work Capability Assessment, while not wanting to ‘write off’ people from the world of work, is clear that there are some exemptions which are reasonable if, based on the evidence received as part of the application process, it is clear that the higher rate would apply. As noted in information provided by DWP for the Employment and Support Allowance: “Although there will be no exempt category in the new Employment and Support Allowance, it will be important to identify, on the basis of paper evidence, those people whose level of severity of functional limitation places them in the support group. It would clearly not be in anyone’s best interests that people with this level of functional limitation should be asked to attend a face to face assessment.”

Thus, someone with a learning disability who has care needs night and day clearly has a severe or profound and multiple learning disabilities and will face significant extra costs associated with their disability as a result. From this perspective, it can be argued that the existing automatic entitlements to higher rate DLA are an efficient and effective way to allocate resources.

**The extent to which PIP will act as a gateway to other benefits**

The Government acknowledges that entitlement to DLA also ‘passport’ the recipients to additional help and support. DLA can link to qualification for other means-tested benefits, as well as services and concessions, for example, eligibility for different rates of Local Housing Allowance. We are concerned that eligibility for Carer’s Allowance could be lost if PIP is removed or reduced below the middle rate care component. We believe it is essential that these links are protected. There could be a number of knock on effects of the proposed changes, which are a serious concern and could potentially exacerbate the effect of the loss of benefit.

**The design of the PIP assessment**

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12 Transformation of the Personal Capability Assessment, DWP, September 2006
The assessment criteria and design

The development of an ‘objective’ assessment is rather undermined by the need to achieve a targeted saving and it is therefore difficult to have confidence in the objectivity of the process.

The impact assessment published alongside the Government’s reform consultation document stated that “[i]t is likely that some disabled people with lesser barriers to leading independent lives will receive reduced support.” If the Government acknowledges that there will be some disabled people who will not be found eligible for PIP (but may have previously received DLA) it is important to get an idea of the sorts of people this might include. Thus, in order to develop an assessment that accurately determines eligibility for PIP there is first of all a need for a clear definition of who should be eligible. The importance of this has also been highlighted in relation to the Work Capability Assessment (WCA) and by members of the work-related activity group of ESA. As was noted in this context, greater clarity around the sorts of claimants intended for this group – i.e. what sort of characteristics, impairments or barriers should define eligibility – would enable a more informed debate as to the descriptors used in the WCA.

Along similar lines, clarity about eligibility for PIP given the confusion surrounding the focus on “greatest need”, the change to two rates of payment for the ‘daily living’ component and the continuation of PIP as an “extra costs” benefit, would allow a more productive discussion about the accuracy of the criteria being proposed. Without this, there is no way of determining whether the benefit is being awarded fairly. This should certainly happen before any discussion of the scoring of the criteria. As they stand, the draft assessment criteria provide no indication of the point awards / thresholds for each of the criteria, which makes it difficult to comment on them.

It is without doubt a challenge to create an assessment that is robust enough to reflect the wide range of disabilities and conditions, and one that can successfully include the ‘impact on everyday life’ proxy (as opposed to ‘care’ and ‘support’ used in DLA), effectively measuring the multi-dimensional drivers that impact on the costs that disabled people incur. It is disappointing that the draft assessment criteria seem to take a very medical model approach in relation to the activities that are included – particularly given the emphasis placed on the social model of disability as per the DLA consultation document and Government rhetoric. The draft criteria focus on the medical impact of an individual’s impairment rather than how this interacts with society to create barriers to independence. Further, by measuring a single factor against certain functional tasks and everyday activities, the wider additional costs that DLA is currently spent on – for example, increased electricity bills associated with doing laundry more often or paying for more expensive specialist clothing – will not be picked up unless we can say confidently that all of the other criteria will ensure this ‘by proxy.’ This is unlikely to be the case in all scenarios.
Assessing mental, intellectual and cognitive conditions and with fluctuating conditions

Given the concerns about how the Work Capability Assessment (WCA) is working for people with ‘mental, intellectual and cognitive conditions’, there is obvious anxiety in relation to the PIP assessment and we have raised a number of potential issues (based on the published draft assessment) around how it will work for people with a learning disability. These include:

- Terminology that does not take into account learning disability – for example, support is considered by use of the terms ‘assistance’ and ‘prompting’, described as either ‘continual’ or ‘intermittent.’ These terms do not cover support that might be more accurately described as ‘supervision’, which is particularly important in relation to the support needs of people with a learning disability;
- As we have continually noted in our work on the WCA, it is particularly important that length of time taken to complete an activity is taken into account in relation to people with a learning disability. Many individuals will be able to complete a task but will take a considerable amount of time to do so which could well adversely impact on their ability to complete other tasks;
- Problems with specific descriptors – e.g. communicating with others: we believe that this activity is trying to assess too many things under one criterion and would be better split into two criteria separating out communication and ability to understand.

More generally, there are some overarching issues with the assessment that are not learning disability specific. For example, the technical note published alongside the draft assessment states that “it would not be practical for the assessment to take account of the impact on ALL everyday activities, nor to seek to include all possible areas where extra costs may be generated.” However, there is a danger of over simplification with an approach like this, and we believe that the draft criteria miss out a number of important factors. The Minister for disabled people has stated several times that the Government is committed to PIP supporting participation and enabling disabled people to lead independent lives, and that the new benefit will be about promoting independence and social inclusion. If this is to be the case, we believe that additional criteria, including utility costs, managing finance and travel related costs should be considered.

The delivery of the PIP assessment

On the WCA, Professor Harrington’s Independent Review stated: “There are clear and consistent criticisms of the whole system and much negativity surrounding the process. There is strong evidence that the system can be impersonal and mechanistic, that the process lacks transparency and that a lack of communication between the various parties involved contributes to poor decision making and a high rate of appeals.” In relation to the Atos healthcare professionals undertaking the WCA, the review also noted that there were “instances of significantly poor treatment by the system or by the Atos HCP”. It will be essential that the issues highlighted in the independent review are properly considered and analysed in the context of the delivery of the new PIP assessment.
How DLA/PIP should apply to children and people over the state pension age?

We welcome the Government’s assurances that there will be some debate and scrutiny of any changes to DLA for under 16s. However we seek a clear timeline against which the Government plans to migrate children onto PIP. A lack of clarity on this issue has resulted in debate in the Commons stage of the Bill focusing on the system for working age adults. There is a valid case for the design of PIP to be different for under 16s.

The steps DWP needs to take to ensure that its reform proposals are clearly and effectively communicated to claimants and the general public

Media coverage of the reassessment of ESA claimants has been misleading (for example, ignoring the numbers being found eligible for the work-related activity group of ESA and looking at those being placed in the support group) and we deprecate the pejorative language which some sections of the press use when referring to benefit claimants. The DWP need to be particularly careful about presentation of their statistical data to avoid creating negative perceptions about disabled people. In addition, it is essential that DWP engages proactively with DLA recipients on all aspects of the proposals, including in relation to the assessment criteria proposals. It is essential that the voices of disabled people are heard and their concerns addressed.

It is important that the government considers the reform of DLA within the context of additional changes to the benefits system. Understandably, disabled people and their families have expressed concern that they feel they are being ‘squeezed’ from all sides. People are becoming increasingly anxious about losing some or all of the support they receive and how (or whether) they will cope as a result.
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 per cent are disabled or have a long-term health issue
   - 15 per cent of our clients are lone parents
   - 15 per cent 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 to 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*¹, 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.

### 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

¹ “Counting the cost” Wood and Grant published by Demos 2010.
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 per cent. 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 disabled2.

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:

15. 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

16. 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

17. 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

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medical model. The medical model doesn’t identify the very different barriers to social inclusion faced by different individuals.

18. **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.

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**The implications of a six month qualifying period.**

19. We are very concerned about the proposal that DLA should have a 6-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 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 per cent 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.

20. 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.

21. 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.

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**The extent to which PIP will act as a gateway to other benefits, including Carers Allowance and the Motability Scheme.**

22. 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.
23. 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

24. 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.

25. 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

26. 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

27. 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.

28. 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.

29. 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.
Thirty seven reports were received. We analysed them and grouped them into three levels of reported accuracy.

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. Sixteen of the 37 cases were judged to be in this group.

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 were in this group.

Eleven of the reports were classified as having a low level of reported inaccuracy.

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.

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

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...

We are working with PDCS to help inform their plans for delivery of PIP.

…..and the general public

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.

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3 The sample size is necessarily fairly small, since this research was intensive and time consuming for bureaux advisers - for a sample of this size for 95% confidence the sampling error will be around 16%
4 43% of the sample - ie there is 95% confidence that the true level of reported inaccuracy is between 27% and 59%
5 27% of the sample
6 30% of the sample
1.1 The DBC is a national coalition of over 50 charities and other organisations committed to working towards a fair benefits system. 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 of the risks involved. Failure to adequately assess the impact and mitigate the risks could see a judicial review of the DLA/PIP plans.

DBC response to individual aspects of the inquiry

- 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 account⁴.

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 inconclusive⁵; and there is also evidence on the number of disabled people not accessing DLA but entitled to support⁶.

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% rate⁷.

3.5 DWP have also suggested that periodic review of claimants is required due to the length of time many disabled people have received DLA⁸. 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 impairments⁹.

- 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;

⁴ See: 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%).
⁸ 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.
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\textsuperscript{10} help demonstrate the implications of reduced DLA/PIP use and support previous research evidence. The Disability Alliance survey on Government plans also found\textsuperscript{11}:

- 62% of respondents feared cuts would increase exclusion and poverty;
- 35% reported finding it difficult or very difficult to get by already;
- 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%).

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\textsuperscript{12}. 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\textsuperscript{13}.

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\textsuperscript{14}.

\textsuperscript{11} 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: \url{http://www.disabilityalliance.org/r68.doc}
\textsuperscript{12} 20% would be £1.3 billion based on 2010/11 working age DLA expenditure.
\textsuperscript{13} See: \url{http://www.disabilityalliance.org/r68.doc}
\textsuperscript{14} 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
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\textsuperscript{15}. 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\textsuperscript{16}, attend medical appointments or pay high utility bills resulting from maintaining a consistent home temperature), resulting in greater numbers of avoidable hospitalisation periods\textsuperscript{17};
- be unable to manage independently and seek cost-intensive council funded residential care\textsuperscript{18};
- 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\textsuperscript{19}.

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.

- \textbf{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

\begin{footnotes}
\footnote{\textbf{The extent to which overlaps in funding exist, particularly with local authority and NHS funding, and including for people in residential care or hospital.}}
\end{footnotes}
support. One is ‘overlap’ in funding. The DBC has responded to all the Government’s attempted justifications\(^2\)\(^0\). 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.

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

\(^20\) See: *DLA mobility: sorting the facts from the fiction* online at: [http://www.disabilityalliance.org/dbcdla2.pdf](http://www.disabilityalliance.org/dbcdla2.pdf)
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 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\textsuperscript{21}.

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 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.

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.

- 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.

22 The DBC supports the recent, similar recommendations made by the Work and Pensions Select Committee.
10.2 Recently, a man found fit for work died whilst waiting to appeal a WCA decision. 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. 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 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.

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.

- **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.

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24 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.

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 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 14th 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 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 DW 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 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 uncertainly 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 do[u]bts 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 (i.e. longer than the recommended timeframe). 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.
1. **About Carers UK**

1.1 Carers UK represents the views and interests of the 6.4 million people in the UK who care for their frail, disabled or ill family member, friend or partner. Carers give so much to society yet as a consequence of caring; they experience ill health, poverty and discrimination. Carers UK seeks to end this injustice and will continue to campaign until the true value of carers’ contribution to society is recognised and carers receive the practical, financial and emotional support they need.

1.2 Carers UK is an organisation of carers, run by carers, for carers. We reach of around 1,500 organisations, including many run by carers, who are in touch with around 950,000 carers. Including Carers Week, our reach extends to around 8,000 groups and 2.5 million carers.

1.3 Carers UK runs an information and advice service and we answer around 16,000 queries from carers and professionals every year. We also provide training to over 2,600 professionals each year. Our website is viewed by nearly 50,000 unique visitors every month and nearly 5,000 carers are registered members of our website forum.

1.4 Carers UK has offices in Wales, Scotland and Northern Ireland. This response reflects the views of the organisation, UK-wide.

2. **Summary**

2.1 Carers UK accepts that Disability Living Allowance (DLA) is an imperfect and overly complex benefit and that there is a case for reform. However we do not accept the case for cutting the budget for disability benefits and do not believe that it is appropriate or practical to combine wholesale reform with substantial cuts.

2.2 We believe that the proposed £2.17 billion cut to the funding available for Personal Independence Payment (PIP) would put at risk some of the most vulnerable disabled and ill people in society, undermining their dignity and independence.

2.3 In addition, our modelling shows that, as the loss or reduction disability benefits brings knock-on impacts to family incomes, the effect could be disastrous to those already struggling to make ends meet. Despite contributing an estimated £119 billion to the UK with the unpaid care they provide, carers receive the lowest benefit of its kind and are often in a financially precarious situation, facing debt and financial hardship as a result of giving up work to care whilst their families cope with the substantial additional living costs associated with illness and disability. Nearly three quarters of Carer’s Allowance claimants are women, all claimants care for at least 35 hours a week but at least half care for more than 50 hours each week\(^1\), many will be amongst the 1 million people who have given up work or reduced working hours to care\(^2\) and the two-thirds of carer households where no-one is in paid

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\(^1\) *Carer’s Allowance customers’ experiences of caring* (2011) Sue Yeandle and Gray Fry, Leeds University

\(^2\) *1 million give up work to care* (2009) Carers UK and Ipsos MORI
work. Over 40% of claimants can expect to care for over 5 years, 17% for over 10 years – many of those who give up work to care will do so in their 40s and 50s, and face retirement on reduced pensions and savings; others, who find their caring responsibilities come to an end before retirement, struggle to return to the workplace.

2.4 As a result of this existing vulnerability to financial hardship, Carers UK believes that carers and their families could be particularly hard hit by the proposed reductions in spending on DLA/PIP, and we are deeply disappointed that this has not been adequately assessed. We continue to urge the Government to reconsider these budget cuts, which we believe would push many disabled people and carers further into financial hardship and would ultimately undermine family care.

3. **Impact assessment**

3.1 Carers UK is surprised and disappointed at the lack of adequate assessment of the impact of the PIP proposals on carers:

- There was no mention of carers in the initial Impact Assessment of the DLA reforms, published with the Bill; or in the Equality Impact Assessments published during the Committee stage. The Government’s response to the DLA reform consultation, published in April, simply states that the Government is considering the implications for Carer’s Allowance of DLA reform.
- This lack of upfront information not only makes adequate scrutiny of the proposals impossible – but it is also causing a huge amount of distress for families, including those affected by the most severe disability and terminal illness, who fear the loss of their disability and carers’ benefits because they do not know if they may be affected.
- Given that 73% of current Carer’s Allowance claimants are women, it is also concerning that the potential loss of independent income for a group predominantly made up of women was not a key part of the gender impact assessment for the Bill.

3.2 We believe that it is critical that a full evaluation of the impact on carers is conducted as a matter of urgency. This must include an estimate of the number of carers expected to lose Carer’s Allowance, a disability impact assessment and a carer equality impact assessment which looks at the impact on gender equality of the likely loss of Carer’s Allowance.

4. **The extent to which PIP will act as a gateway to Carers Allowance**

4.1 Currently, eligibility for Carer’s Allowance is established through the middle or higher rate care components of DLA. Instead of three rates within DLA (lower, middle and higher), PIP will have only two rates; standard and enhanced. The Welfare Reform Bill does not establish how existing groups of DLA claimants will fit into these new categories.

4.2 Whilst the Government has confirmed that PIP will be the gateway to Carer’s Allowance, they have not stated which level of the ‘daily living' component would lead to eligibility for Carer’s Allowance. We are concerned that, if eligibility were set at only the enhanced rate, substantial numbers of carers could lose entitlement to Carer’s Allowance, without their caring responsibilities having changed.

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3 Facts about Carers (2009) Carers UK
Currently 565,000 carers are in receipt of Carer’s Allowance. In response to a Parliamentary Question in May 2011, the Minister for Disabled People stated that data does not exist on the division of Carer’s Allowance claimants caring for the disabled people on a) the middle and b) the higher rate of Disability Living Allowance, and that the costs of the analysis required would be disproportionate. However we believe that it is reasonable to assume that thousands of carers could lose entitlement to Carer’s Allowance if the Government established eligibility only at the enhanced rate of PIP. The impact on families of losing entitlement to Carer’s Allowance is set out in section 5.

Carers UK is deeply concerned that the Government has not yet come to a decision on eligibility for Carer’s Allowance, particularly given the advanced stage of the legislative process for the Bill. In addition, the response to the Written Parliamentary Question above indicates that the Government may not have conducted an impact assessment of the options.

The implications of reduced expenditure

Carers UK is strongly opposed to the Government’s decision to cut 20% of the funding available for DLA/PIP. Given that the fraud rate for Disability Living Allowance is 0.5% it is clear that a 20% cut would result in the reduction in or removal of disability benefits for large numbers of legitimate claimants – with both direct and indirect consequences for wider family incomes.

Cuts of this size would compromise the dignity and independence of disabled people and those with long-term conditions who are able to live independently. In addition to clear implications for disability poverty, outlined in detail in the Disability Benefits Consortium response to this inquiry, the cut could only serve to undermine disabled people’s quality of life and the Government’s objectives to promote independent living. It may also ultimately incur additional costs to the Exchequer – as a loss of independence leads to greater demand for higher level disability benefits or care and support services.

The reduced expenditure would result in serious financial consequences for families. Carers UK research consistently shows most carers are financially worse off as a result of caring:

- 74% were struggling to pay essential utility bills
- Over half were cutting back on food to make ends meet (52%)
- 66% were using their own income to pay for care for the person they cared for
- 54% were in debt as a result of caring

The resulting loss of independence for disabled people would lead to indirect additional financial pressure on carers. Already, we know that two thirds of carers use their own incomes to pay for care for the people they look after, reductions in incomes from disability benefits would only increase the pressure on carers to dip into their own incomes to pay for support for the people they care for.

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4 HC Deb 02 May 2011 cc532W-533W
5 Of 1,734 carers responding to a survey Carers in Crisis (2008) Carers UK
5.5 Reductions in income would also reduce disabled people’s capacity to pay for support with transport, aids and adaptations and personal care. Added to estimated £1 billion in cuts to social care services this year, and a similar amount next year\(^6\) - there is a real risk that the combined financial and practical impact on families could be disastrous.

5.6 As set out in the previous section, it is possible that carers will lose Carer’s Allowance as a result of possible changes to eligibility rules. However the scale of the proposed cuts could also lead to substantial numbers of carers losing Carer’s Allowance as the people they care for see their disability benefits reduced or removed.

5.7 The Government has not published estimates of how many disabled people would expect to see their benefit level reduced, or DLA removed entirely, or where the cuts would fall amongst the DLA components and rates. Again, this makes it impossible to effectively assess the impact on carers.

5.8 This lack of information is not only unhelpful as organizations attempt to assess the impact of these measures – but it is also causing a huge amount of worry and distress to families, including those affected by the most severe disability and terminal illness, who fear the loss of their disability and carers’ benefits.

5.9 In the absence of DWP estimates, organizations like Disability Alliance have attempted to estimate the numbers of DLA claimants who would be affected to achieve a 20% reduction in expenditure. Disability Alliance analysis also indicates that, even if all recipients of the lower rate care component lost their benefit (this would not affect any claims for Carer’s Allowance), that the savings announced by Government would require substantial additional cuts to benefits for claimants in receipt of the middle or higher rate care component (where Carer’s Allowance eligibility is established). Disability Alliance estimates that as many as 740,000 disabled people could be affected in total\(^7\) and it is likely that changes to groups currently receiving the middle and higher rate care component, would result in the removal of Carer’s Allowance linked to their claims.

5.10 Carers UK argues that cuts of this scale put at risk some of the most vulnerable families, particularly families in which no-one is able to engage in paid work due to severe disability and caring responsibilities. These families may also be struggling with a lack of access or cuts to good quality and flexible care and support services. The loss of hundreds of pounds a month of income from carers and disability benefits could be devastating for families who are often already struggling to make ends meet.

5.11 **Case study:** Tony gave up work to care for his wife Laura who is partially blind and has memory problems following a car accident. They have two young children. Laura needs Tony to be there to help her wash, dress and use the toilet and she struggles to prepare food on her own. Tony would love to go back to work but does not want to leave Laura on

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\(^6\) ADASS Budget Survey 2011 (2011) The Association of Directors of Adult Social Services

\(^7\) Disability Alliance estimates that, in order to achieve £1 billion in savings, there would be a risk to the DLA of 643,000 disabled people receiving the lower rate payment of care (£634 million per year) and a further 100,000 disabled people on the middle or higher rate care components or the higher rate mobility component.
Tony claims Carer’s Allowance and Laura receives the middle rate care component of Disability Living Allowance. The family is also having the support they receive from care and support services reduced because the local authority has just raised their eligibility criteria to ‘critical’ needs, and Laura has been assessed as having ‘substantial’ needs.

If, following assessment for the new PIP, Laura’s received a reduced amount of disability benefit, which did not allow Tony to qualify for Carer’s Allowance - the family could lose almost £60 a week, over £230 a month, through the reduction in disability benefits, the removal of Carer’s Allowance and Carer Premium. Tony would be forced to claim Jobseeker’s Allowance even though he knows he cannot work because of the care and support his family need and the fact that their social care services are being cut back.

5.12 There is the real risk that the effect of this would be to undermine family care. Nearly nine in ten (87%) working age carers providing round the clock care to disabled partners had no-one in the household in paid work – these families would be the hardest hit by reductions to their financial support from the benefits system, and many would be unable to continue caring. This would force some families to call on local authorities to step in and provide full home care packages or admit the person they care for into residential care, at a potential cost of thousands of pounds a month.

6. Mobility component in residential care

6.1 Carers UK is a signatory to the Mencap report Don’t Limit Mobility which sets out the united opposition of the disability sector to the Government’s plans to remove the mobility component of DLA from individuals in residential care settings. The proposal would trap individuals in their own homes by removing the money they use for transport and mobility vehicles. Mobility component can be key to personal independence to disabled people in residential care, enabling them to engage in social activities, volunteering, work and hobbies outside of their homes.

6.2 Families who use DLA mobility component to fund Motability vehicles could face losing their family cars, which would be particularly difficult for parents of disabled children who attend residential schools.

6.3 Case study: Stephen and Kiranjit care for their disabled daughter Lucy and the family use their Motability car to go out together and her to residential school, which is in a rural area 40 minutes away. As a result of lung damage, Lucy frequently falls ill during term and needs to come home. Without the use of this car the family would struggle to do any of these things, and could not afford the taxi costs of coming to visit Lucy frequently at school. Lucy’s parents feel strongly that she has a right to spent time with her family, particularly her brothers and sisters.

6.4 As outlined in the Mencap report, we strongly refute the Government’s assertion that, in these circumstances, the mobility component amounts to double funding. Particularly at a time of tight local authority spending, it is completely unrealistic to expect social care budgets to be able to absorb the additional expense required to achieve the kind of
individualized support that individuals can achieve by choosing how to spend their mobility component.

7. **Assessments**

7.1 We believe that it is crucial for the new PIP assessments to look at a wide range of evidence, rather than prioritise a ‘snapshot’ face-to-face meeting with a medical generalist, which may fail to gather comprehensive evidence of fluctuating or complex conditions. We endorse the concerns expresses the Disability Benefits Consortium around the proposed assessments, and urge the Government to learn the lessons from the Harrington review and ensure a wide evidence base is built-in to the proposed assessment.

7.2 Those with the most comprehensive picture of the impact of an illness or disability are also likely to be families providing care round the clock. The National Carers Strategy, refreshed by the current Government in November 2010, states that carers must be treated as ‘expert care partners’ by professionals – to reflect their knowledge and expertise in caring for the people they look after. To fulfil these aims, and to ensure that the most comprehensive picture of disability is arrived at, we urge the Government to build carers’ views into the assessment process.

7.3 This is well illustrated by an example from the Aberdeen trials of the Work Capability Assessment, where families have reported a real lack of clarity about their capacity to contribute to the assessment process. Carers UK has heard about a man in his twenties with a learning disability, whose mother’s views were not requested as part of his assessment, and, as a result, his epilepsy was not recorded, because he was not able to describe the symptoms in his interview.

8. **The implications of a six month qualifying period**

8.1 Proposals in the Bill would extend the qualifying period for the new Personal Independence Payment to six months rather than the existing three months. Carers UK strongly disagrees with this, as the impact on families of having to wait for six months before receiving financial support from both disability and carers’ benefits could substantially increase family debt and financial hardship.

8.2 We know from calls to our Adviseline, that the greatest pressure on family finances often comes in the first months of caring, where a number of factors combine: lost earnings as a result of illness or disability, additional living costs associated with disability, additional travel costs for medical checkups and hospital appointments, a lack of advice and information delaying family’s access to financial and practical support.

8.3 This measure would have the biggest impact on families coping with a sudden, unexpected illness or disability who face the loss of two incomes – though disability and caring responsibilities. For example, a couple in which one individual is disabled following a road traffic accident and the other gives up work to care, would have to wait for six months before receiving PIP or Carer’s Allowance despite losing two full-time salaries. This could leave families in lasting debt and financial hardship if they face long periods on low-level benefits as a result of illness or disability. Carers UK survey work shows that debt and financial
hardship are already prevalent amongst families providing care – with 75% struggling to pay basic household bills and over half in debt as a result of caring.8

8.4 We strongly urge the Government to reconsider these changes which could push families into long-term debt which they have little capacity to pay off if they face an extended period in receipt of disability and carers’ benefits. Families facing such decisions may make the decision that they are financially unable to take on care, again with knock-on implications for health and social care budgets.

9. Transitional arrangements

9.1 Carers UK agrees with the Disability Benefits Consortium’s view that ‘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’.

9.2 If the Government continues to push ahead with plans for substantial cuts in the DLA/PIP budget, in addition to measures to protect disabled people who face reductions in their benefits following reassessment, it is essential that transitional protections will be put in place for carers who lose Carer’s Allowance as a result. If no transitional protections are put in place this could result in significant numbers of caring relationships breaking down, with clear knock-on implications for local authority care and support budgets.
1 Introduction:
Creative Support provides a range of services including supported living, supported housing, residential care, community and home support, floating support, extra-care and day services. We work with people who have a wide spectrum of needs, ranging from those who require short term support to regain their independence to people with complex needs who require intensive support to enjoy a good quality of life.

We have consulted with both members of staff and our service users to obtain their views on this consultation. Therefore this submission addresses the proposal from the views of people with mental health issues as well as those with a learning or physical disability.

2. How is the process for claiming DLA viewed and does it need replacing.
DLA is a complex benefit to apply for. The form that has to be completed is extremely long and includes confusing questions leaving people feeling confused, degraded and upset. The process for claiming DLA takes a long time and appeals can often take over six months to be completed. The process can cause a lot of distress for claimants. This is due to the actual process used as well as the delays incurred whilst waiting for a decision or appeal. These delays can impact on a person both financial and within their own community. Receipt of DLA has a direct impact on the amount of ESA or IS that someone receives. In addition the receipt of high rate DLA mobility means that people can apply for a motability car to access the local community where public transport is not appropriate. Currently the form is more focussed to individuals with a physical disability rather than a mental health problem and does not take into account the impact that this can have in everyday life.

Proposal:
PIP need to be simplified and be made more user friendly. It needs to assess individuals in a person centred way. There needs to be more focus on the impact that mental health problems can have.

3. Why do you think the DLA caseload and expenditure has increased?
People are more aware of the benefit and whether they are entitle to apply for it. Over the last ten years there has been a dramatic increase in the number of people that have moved from hospitals and residential care to their own home in the community. Where before they were not entitled to DLA care or had not made a claim, they are now in a position where they can claim DLA. We are also living in a society where people are living longer and therefore are receiving DLA for longer periods of time.

Proposal:
The expenditure for DLA should not be cut as the people that need it the most will be the ones most affected. Instead the Government should be looking at ways to prevent benefit fraud as a way to reduce the expenditure.

4. The impact of having only two rates in each component of PIP?
People on low rate DLA are often awarded this rate as they need support with cooking a meal, personal care or getting support when going out to unfamiliar places. If this element is removed this will have a direct impact causing people to stop accessing their local
community such as the shops, doctors and hospital and they would become isolated from their community. Their diet could be affected having an impact on their health and we could see a deterioration in personal hygiene and care. It is important that the low rates are not removed as they are a much needed additional income to support individuals to improve their standard of living and encourage social engagement.

Likewise if the high rate of care was removed this would have an impact on those that need support throughout the night and would put people at risk both physically and mentally.

Proposal:
PIP should continue to offer three rates of DLA care as the encompasses a range of varying needs.

The criteria for those applying for high rate mobility under the rule of having a SMI is extremely restrictive and very few people meet it. There are numerous cases where an individual is unable to use public transport as they have a severe mental health problem that and require either a motability car or additional income for regular use of taxis but do not meet the SMI criteria.

Proposal:
Amend the criteria for high rate mobility to take into account claimants with mental health problems.

5. How should automatic entitlement and awarding people for indefinite periods work.
If a condition is an on-going or a terminal illness then there should be an automatic entitlement. If the condition is one that is not going to improve and there should be an entitlement of an indefinite period. This would reduce the stress of applying for some claimants and reduce waiting times. It should include individuals with certain disabilities and mental health problems and not be restricted to terminal illnesses.

Proposal:
Develop automatic entitlement for individuals with enduring and severe mental health problems or disabilities that are not going to improve.

6. Assessments
If the PIP assessment is going to be conducted similar to that of ESA it needs to be taken into account that the process for claiming ESA is extremely stressful and complicated. The questionnaire is complicated and demoralising and is geared more to those with a physical disability and does not take into account fully an individual with a mental health problem. The actual medical exam is conducted on average in twenty minutes and does not allow time for the medical examiner to understand the individual's condition. Often the outcome of the claim has been incorrect and has not taken into account the information that has been provided and an appeal has to be done. This can take up to eight months to process having a negative impact both mentally and financially.

Our service users want to be assessed in a person centred way that addresses their individual pertinent needs whiles upholding their dignity. This should involve local GPs, hospitals and the Community Mental Health team who are aware of the person’s condition and needs. This should centre on spending time with the person to see what they can and can not do rather than a tick box exercise.
Proposal:
- Simplify the procedure.
- Ensuring the assessment is person centred.
- Include professionals that are involved in the individuals care in the assessment.
- Ensure the criteria fully take into account mental health problems in the assessment.
- Conduct assessments that look at all the evidence.
- Reduce appeal times.

7. Promoting the changes
Often people do not apply for DLA as they are not aware that they are eligible, the process is complicated and stressful, they need support to apply and are not aware of their medical condition or see themselves as having a disability.

Proposal:
The changes need to encompass a campaign that targets those on DLA and those that may be eligible to ensure that no-one is excluded and that all claimants are aware of the changes and where they can go to for advice. This needs to include the following.
- Clearer instructions
- Helpline for completing claims
- TV
- Letters
- Specialised staff to support people claiming

Summary:
- PIP need to be simplified and be made more user friendly. It needs to assess individuals in a person centred way. There needs to be more focus on the impact that mental health problems can have.
- The expenditure for DLA should not be cut as the people that need it the most will be the ones most affected. Instead the Government should be looking at ways to prevent benefit fraud as a way to reduce the expenditure.
- PIP should continue to offer three rates of DLA care as the encompasses a range of varying needs.
- Amend the criteria for high rate mobility to take into account claimants with mental health problems.
- Develop automatic entitlement for individuals with enduring and severe mental health problems or disabilities that are not going to improve.
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- Simplify the procedure.
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- Include professionals that are involved in the individuals care in the assessment.
- Ensure the criteria fully take into account mental health problems in the assessment.
- Conduct assessments that look at all the evidence.
- Reduce appeal times.
- Simplify the procedure.
- Ensuring the assessment is person centred.
- Include professionals that are involved in the individuals care in the assessment.
- Ensure the criteria fully take into account mental health problems in the assessment.
• Conduct assessments that look at all the evidence.
• Reduce appeal times.
• The changes need to encompass a campaign that targets those on DLA and those that may be eligible to ensure that no-one is excluded and that all claimants are aware of the changes and where they can go to for advice. This needs to include the following.
  - Clearer instructions
  - Helpline for completing claims
  - TV
  - Letters
  - Specialised staff to support people claiming
1. Introduction

Inclusion London (IL) welcomes the opportunity to respond to the Work and Pension Select Committee’s call for evidence regarding the government’s plans to replace Disability Living Allowance (DLA) with ‘Personal Independence Payment’ (PIP).

Inclusion London
Inclusion London is a London-wide organisation which promotes equality for London’s Deaf and disabled people and provides capacity-building support for Deaf and disabled people’s organisations in London.

Inclusion London’s Response
In this paper Inclusion London gives a summary of our views followed by a response to the questions posed by the select committee, which are included in the terms of reference.

2. Summary

Inclusion London believes that DLA needs reforming. However, we are extremely concerned that the plans to abolish DLA and replace it with PIP will increase the poverty and disadvantage of disabled people, particularly the proposal to cut expenditure and the number of claimants by 20%. We, therefore strongly oppose the introduction of PIP.

We are also very concerned that people’s understanding of DLA has been blurred by government and the media, giving a distorted view of DLA claimants as fraudulent scroungers who are dependent on

1 http://www.parliament.uk/business/committees/committees-a-z/commons-select/work-and-pensions-committee/inquiries/dla/

benefits. While on the contrary, DLA supports disabled people in overcoming the barriers to independence, which is understood by many claimants.

The government’s agenda for reforming DLA is driven by their requirement to cut expenditure on the benefit by 20%. In their haste to push this agenda forward the government has ignored important facts concerning disabled people which include:

- Between 650,000 and 1.8 million disabled people will fall further into poverty is the likely impact of focusing on those with the ‘greatest need’ and the two rates of DLA.
- Cutting the mobility component of DLA from residents in care homes will decrease the ability of 80,000 disabled people to participate in the community.
- The DLA assessment process is already rigorous, which is reflected in the low level of fraud (0.5%), therefore there is no reason to change it.
- One of the reasons for the increase in the number of claimants is demographic change, e.g. the general population is getting older so DLA claimants are living longer.
- The number of claimants has risen by about 13 per cent a year rather the 29 percent that has been reported in the media.
- The six month qualifying period will seriously disadvantage those with fluctuating conditions, terminal illnesses, and those that have recently become disabled.

Design of the Assessment

Inclusion London believes that:
- The Assessment Design group should have an equal number of disabled people to health and social care professionals and government officials.
- The proposed assessment focuses only on what a person can and cannot do, while it should look at the extra costs incurred by disabled people.
Assessment Criteria

- The design of the assessment criteria should take the ability to walk up and down steps and the ability to read correspondence into consideration.
- The criteria needs additional wording to accurately assess those with mental health and fluctuating conditions and those with pain and fatigue.
- The use of aids and appliances should not disqualify a claimant and the cost of the maintenance and replacement of equipment should be taken into consideration.

Delivery of the assessment and contracts:

- We recommend that the assessors have a good knowledge of the social model of disability and an expertise in the impairment of the person that they are assessing.
- Disabled people need to be at the heart of designing the work specification for the contract.

Lessons learnt from the Harrington WCA review include:

- More time is needed for each assessment.
- A copy of the assessor’s report to be provided automatically for each claimant at a stage when it can be challenged for inaccuracies.
- The design of the customer survey needs include questions that enlist accurate feedback about the whole process of the assessment.

Other responses include:

- Automatic entitlements avoid stressful and expensive reassessments.
- PIP should continue to act as a gateway to other benefits and concessions in the same way as DLA.
- Children and older people need DLA or PIP or a similar benefit that includes a mobility component.
• An awareness campaign is needed that stresses the role DLA/PIP plays in supporting the independence of disabled people.

3. Inclusion London’s Response

Inclusion London has responded to the Work and Pensions Select Committee’s questions below. We have not answered all the questions.

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.

Inclusion London will respond to each section of this question as follows:

❖ The need for DLA reform

3.1: The process of applying for DLA needs improving, for instance visual impairment, mental health and fluctuating conditions should be recognised in the assessment process. However, there is no need for abolishing DLA and replacing it with Personal Independence Payment (PIP). This reform seriously disadvantages disabled people, particularly the intention to remove the benefit from 20% of claimants.

❖ How well understood DLA is

3.2: Awareness of DLA is low amongst the general public and most disabled people depend on an advisor for information and support to apply for the benefit. However, many claimants understand that DLA helps pay for the extra costs of being a disabled person.

3.4: However, the government has repeatedly sought to blur the public perception of DLA, with statements which mention
‘dependence’ on benefits and the advantages of employment. This is irrelevant because DLA can be claimed regardless of whether a person is employed or not. In fact many disabled people have said that they would be unable to work without the benefit. As the Work and Pension’s Committee (WPC) is well aware, the tabloid media has compounded this by painting a picture of disabled people as benefit scroungers and ‘handouts for disability’.

3.5: In fact, only 1.8 million out of an estimated 7 million disabled people of working age in the UK receive DLA. Many people that are eligible for DLA do not claim the benefit. This was recognized by the previous government’s Work and Pension’s Select Committee who recommended an awareness campaign. The government has chosen to ignore this recommendation, as well as the low percentage of disabled people claiming the benefit so they can continue their harsh programme of cuts.

Why the DLA caseload and expenditure has increased

3.6: The reasons why the number of claimants for DLA has risen include demographic change for instance:
- The population is increasing as a result there are more disabled people.
- As with the general population, disabled people are living longer and therefore claiming DLA for longer.
- A greater percentage of disabled babies and children are surviving due to improvements in medicine.

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3 ‘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 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’ Marie Miller, Minister for Disabled People: http://www.dwp.gov.uk/docs/dla-reform-consultation.pdf
5 http://www.express.co.uk/posts/view/263830/Handouts-for-disability-have-soared-185-
6 http://www.disabilityalliance.org/dlatest3.htm
7 http://www.dlf.org.uk/content/key-facts
3.7: The report, ‘Disability Living Allowance: Growth in the Number of Claimants 2002/03 to 2010/11’\(^8\) mentions a 29 per cent increase in the number of claimants in a year. However, the actual number of working age claimants is closer to 13 per cent\(^9\), also the number of new claimants has been falling each year\(^10\). The report itself puts a caveat on the 29 per cent figure\(^11\), yet the government ignored this, using the figure of 29% to justify its Welfare Benefit reforms, including the introduction of a face to face interview for PIP.

**Effectiveness of the decision-making and review process for DLA**

3.8: Inclusion London believes that the decision-making process is effective under DLA, because there is a very low level of fraud amongst claimants, (0.5%\(^12\)). In addition 52 per cent \(^13\)of all claims for DLA are turned down, which indicates that the present system is both rigorous. The government has chosen to ignore this because their agenda is to cut the number of people receiving DLA by 20%. Therefore Inclusion London strongly opposes the government’s intention to impose the PIP eligibility assessment.

**Review process for DLA**

3.9: Under DLA there is already a requirement to inform the DWP of a change in circumstances and as mentioned above there is a low level of fraud, therefore we do not think a review process is necessary.

\(^8\) http://statistics.dwp.gov.uk/asd/asd1/adhoc_analysis/2011/DLA_Growth_in_Caseload_FINAL.pdf
\(^10\) http://touchstoneblog.org.uk/2011/08/why-are-there-more-dla-claimants/
\(^11\) The number of DLA claimants has grown by 29% over the last eight years (Figure 1). Essentially the drivers for this growth can be categorised as: changes in the size of the population; changes in the age structure of the population; the “maturity” of the benefit …… ’ Also ‘There have been substantial increases in receipt per head among those aged 65 and over as a result of the ‘maturing’ of DLA’. This distorts the overall picture of growth'.
\(^12\) http://research.dwp.gov.uk/asd/asd2/dlafraudjuly05.pdf
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.

3.10: It is not clear how the government will achieve its 20% reduction in expenditure on PIP, also it is not clear how the assessment criteria will be implemented, therefore it is difficult to estimate whether all the 1.8 million working age claimants will be affected or not. For instance, if the amount of benefit received is reduced then all claimants could be affected. Also it is likely that those on the low rate of the care payment of DLA will lose the benefit all together, which will impact on 643,000 people14.

3.11: The government speaks of targeting PIP at those in the ‘greatest need’. However, the level of the impact of DLA on the independence of a disabled person needs to be considered, as those with a less acute impairment often benefit from their DLA as much as those who are severely disabled.

3.12: The government has not provided evidence that disabled people who are assessed as not having the ‘greatest need’ or are on the low rate do not need or deserve the benefit, because the government has not adequately tested or carried out an adequate Equality Impact Assessment to show the likely impact of this change.

3.13: Inclusion London is strongly opposed to the reduction of expenditure by 20% and the two tier rate of PIP for the following reasons:

Disabled people
- face extra costs due to their impairments that add approximately an extra 25% to expenditure compared to non-disabled people15

14 http://www.disabilityalliance.org/r68.htm
• are twice as likely to live in poverty than non disabled people\textsuperscript{16}
• more likely to live in poverty today than they were 10 years ago\textsuperscript{17}
• are likely to be lower earners than non-disabled people\textsuperscript{18}.

\begin{itemize}
\item The extent to which overlaps in funding exist, particularly with local authority and NHS funding, and including for people in residential care or hospital.
\end{itemize}

3.14: Cutting the mobility component of DLA/PIP from those in care homes is likely to impact on 80,000\textsuperscript{19} disabled people who will have little chance of travelling outside of their care home, reducing social and educational life and participation in the community at large. This will impact on young disabled people because many live in care homes due to a shortage of accessible housing. The government has little evidence for this decision, for further information see ‘DLA mobility: sorting the facts from the fiction’ report compiled by thirty eight charities\textsuperscript{20}.

\begin{itemize}
\item Whether automatic entitlement should apply to people with some conditions or impairments and whether some people should receive awards for indefinite periods.
\end{itemize}

3.15: The provision of automatic entitlements avoids stressful reassessments for the claimants and costly bureaucracy, we would recommend that the present system under DLA continues, where disabled people with permanent, lifelong impairments have automatic entitlements.

\textsuperscript{16} Parckar, G, Disability Poverty in the UK, Leonard Cheshire Disability, 2008
\textsuperscript{17} Parckar, G, Disability Poverty in the UK, Leonard Cheshire Disability, 2008
\textsuperscript{18} Labour Market Disadvantage among disabled people, Centre for Analysis of Social Exclusion, 2005
\textsuperscript{19} http://www.disabilityalliance.org/r68.htm
\textsuperscript{20} http://www.disabilityalliance.org/dbcdla2.htm
The implications of a six month qualifying period.

3.16: The extension of the qualifying period to six months, which will disadvantage many including those who have fluctuating but disabling conditions such as bi polar depression or Multiple Sclerosis. Bouts of illness that last 5 months have a devastating impact of daily life, yet a claimant will not qualify. Those that have recently become disabled or are terminally ill will also be hit hard.

The extent to which PIP will act as a gateway to other benefits, including Carer’s Allowance and the Motability Scheme.

3.17: It is important that PIP acts as a gateway to benefits and concessions in the same way as DLA does; this should include eligibility for the follow benefits:

- Housing Benefit
- Council Tax Benefit (CTB)
- Carer’s Allowance
- Enhanced and Severe Disablement Premium
- Invalid Care Allowance
- Disabled person’s railcard
- Freedom Pass (free travel on London Transport)
- Blue Badge
- Taxicard (reduced fares on London taxis)
- Mobility scheme
- National bus pass
- Refund on road vehicle tax

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

We will answer each section of this question as follows:
The design of the PIP assessment:

3.18: The government guidance on DLA states that ‘Disability Living Allowance (DLA) is not based on your disability but the needs arising from it’. This is not reflected in PIP and the draft eligibility assessment.

3.19: The Assessment Design Group, which created the assessment, was primarily composed of health and social care professionals. Only one person representing disabled people was involved. The group should have included at least an equal number of disabled people as government and other officials, because the composition of the group has had an impact on the design of the assessment. As it stands, the assessment involves a rigid set of questions which examines what a disabled person cannot or can do, which do not address the barriers and extra cost that disabled people experience. This method of assessment follows the medical model of disability. Inclusion London opposes the introduction of any such assessment and believes the assessment process under DLA should remain.

3.20: Inclusion London would like to see an objective assessment of actual extra costs incurred by disabled people in overcoming the barriers to independent living and full participation in society, which would follow the social model of disability. However, the government dismissed this approach as too complex and expensive. Yet the fees for the health professionals that will carry out the face to face assessments on majority of claimants are likely to make PIP assessment much more expensive than the DLA assessment.

Assessment criteria

3.21: Regarding the design of the assessment criteria Inclusion London suggests the following:

http://www.direct.gov.uk/en/MoneyTaxAndBenefits/BenefitsTaxCreditsAndOtherSupport/Disabledpeople/DG_10012424

• Under ‘Communication with others’ another category is needed which covers the ability to access correspondence. This is particularly important for blind and partially sighted people.

• A person may be able to walk 50 or 200 metres on one day but none on another. They may be able to walk short distances on a flat surface but be unable to walk up and down steps. An assessment of these factors is needed.

• Additional consideration of the impact of pain and fatigue is essential, to do this each descriptor should include the wording, ‘repeatedly, reliably and safely, without significant pain, fatigue or distress’.

3.22: For additional comments regarding the assessment criteria please see Disability Alliance’s and the Disability Benefits Consortium response which Inclusion London supports, available at:
http://www.disabilityalliance.org/r71.htm
http://www.disabilityalliance.org/dbcpip.htm

3.33: For more details of Inclusion London’s concern’s regarding PIP please go to:
http://www.inclusionlondon.co.uk/inclusionlondonopposestheintroductionofpipassessment

● Whether the assessment can objectively assess those with mental, intellectual and cognitive conditions and with fluctuating conditions

3.34: Inclusion London believes that an accurate assessment of those with fluctuating and intermittent conditions is crucial for the assessment of those with mental health difficulties. We agree with the Disability Benefits Consortium’s23 and MIND’s24 suggestion that it is necessary to ask about the ‘frequency, severity and duration’ of a

23 http://www.disabilityalliance.org/dbcpip.htm

claimants condition, in order to capture an accurate picture of the
impact of a claimants impairment.

3.35: For further points please see Mind’s June 2011 response which
Inclusion London supports, available at:
http://www.mind.org.uk/assets/0001/3612/Mind_response_to_Draft_A
ssessment_Criteria.pdf

➢ Extent to which aids and appliances should be taken into
account in the assessment.

3.36: We are concerned that those that use aids and appliances,
such as a wheelchair, continue to qualify for PIP as barriers to
independence do not necessarily disappear with the use of a piece of
equipment e.g. wheelchair users face major barriers to mobility in
London, because many underground stations are not step free. Also
the cost of maintaining or replacing equipment and aids needs to be
taken into account.

➢ 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.

Not all sections of this question have been responded to.

❖ Who should carry it out

3.37: Inclusion London strongly recommends that the professionals
have a good knowledge in the social model of disability and an
expertise in the impairment of the person they are assessing.

❖ Approach to tendering for the assessment contract
3.38: Disabled people need to be at the heart of designing the work specification. Compulsory equality training and training in the social model of disability should be part of the specification.

3.39: The track record of providers needs to be considered. Many decisions made by ATOS’s assessors concerning the WCA assessment have been turned over at appeal. Given this track record we strongly recommend that ATOS is not contracted to provide the assessors for the PIP assessments.

- **Whether there are lessons to be learned from the Harrington Review of the Work Capability Assessment**

3.40: Lessons that need to be learned from the Harrington Review of WCA include the following:

- More time is needed for each assessment than the 46-49 minutes provided at the moment, so a personalised assessment is provided, which gives a more accurate picture of how the claimant is disabled by their impairment.
- A copy of the assessor’s report to be provided automatically for each claimant at a stage when it can be challenged for inaccuracies.
- The guidance given to assessors should be provided to all claimants in accessible formats.
- The complaints process should be clear and easily assessable.
- The monthly customer survey should be designed so it gathers the information that will give an accurate picture of the assessment process. To do this it should in include questions on:
  - How accurately the report reflects the information the claimant’s gave to the assessor.
  - The manner in which the assessment is carried out, (i.e. does assessor give adequate time for the claimants to answer the questions and are they respectful etc).

- **Interaction with other assessments**
We have not responded to this question.

- **How DLA/PIP should apply to children and people over the state pension age**

3.41: We have serious concerns that those over 65 years will not be eligible for PIP, particularly as the alternative benefit, Attendance Allowance, does not contain a mobility component. This wrongly seems to presume that older people do wish to mobilise either in doors or out into the community. Likewise there seems to be a presumption that children do encounter extra costs because of their impairment, which is obviously not so, therefore the provision of a welfare benefit is necessary.

- **The steps DWP needs to take to ensure that its reform proposals are clearly and effectively communicated to claimants and the general public.**

3.42: As mentioned above there is a lack of awareness about DLA amongst the general population as a result many of those eligible do not claim, therefore an awareness campaign is needed.

3.43: PIP will contribute towards the extra costs disabled people incur, which will increase independence, this needs to be emphasized by the government, rather that labeling claimants as dependent. As mentioned above, there considerable concern regarding the way the government and the media has communicated with the general public regarding the Welfare Benefit reforms, resulting in an increase in disability hate crime.²⁵

⁵ http://www.guardian.co.uk/society/2011/may/14/disabled-face-increasing-hostility-strangers


➢ Transitional arrangements

We have not responded to this question.

4. Conclusion

In brief, Inclusion London opposes the replacement of DLA by PIP as it will cause further poverty and disadvantage to disabled people.
Written evidence submitted by Sofie Rosemary Haidon (PIP 15)

If there is a 6 month test, then it would mean the claimant losing a lot of money. (even on lower care and mobility that’s almost £500 over 3 months – currently, to qualify, it’s 3 months backwards) Only having 2 rates would mean that many would miss out, yet they still have care needs and still have costs. If some people miss out, good bye to blue badge, bus pass, disability premiums (even on low rate care, low rate mobility and premiums that’s over £3500 a year) and working tax credits. This may also mean their care gets withdrawn. These people would then be financially worse off. Is it right that a disabled person should be worse off due to disability? Many may have to choose between care and having to eat – is that right? Some people would also have to choose between working fewer hours due to disability and being worse off, or having to work full-time and making themselves ill.

Looking at the proposed criteria, it seems as though many people will miss out, yet they still have care and mobility needs. Or is it acceptable for someone not to be supervised and cause themselves and others serious injury? Is not having a social life acceptable too? Even though isolation will cause depression and other mental health issues?

It is not right that some people should be constantly assessed – people were / are given indefinite awards under DLA because it’s believed that their needs won’t change. There really is no point constantly assessing someone in that situation. It’ll cost money and will cause unwanted stress to the claimant. However, I think the right payments programme should continue.

It makes no sense to have tick boxes – many people have care and mobility needs but don’t fit those criteria. The current DLA format is better – because there’s a question, yes and no box and a box to give additional information. This also makes it easier where people can say “if I do this, this will happen”.

Aids should only be taken into account if they are used. It’s unreasonable to say “claimant can do this if they have a piece of equipment costing a few hundred” – unless of course, someone is willing to fund that piece of equipment. Not all claimants are lucky enough to save enough money to buy equipment they need or the NHS says they need.
Everyone should be assessed – it shouldn’t be “you have this condition; so should get PIP”. The only exception should be terminal illness – they should get their benefits paid as soon as and not have to wait around to be assessed.

The only people who should assess claimants are people who know what they are doing. I am having constant battles with DWP because they have somehow decided I don’t have the most common side effects of my disabilities – yet, 99% of people with the same condition have the same side effects.

People in residential care should be able to get the mobility component. They have as much right to go out as everyone else. The local authority shouldn’t have to pay for this as well – where would the money come from? For people in care who use the Motability scheme – that would mean either finding someone with an adapted car who is willing to take them out. They would lose their blue badge and maybe their bus pass – how are they expected to get out if they can’t park close to their destination?

PIP should also apply to people over pension age and children. It is not right that these people should undergo different tests just because of their age.

If I lose DLA, I won’t be able to pay for the adapted mobile phone I need, the wheat free food I need, the shoes I need to constantly replace, the extra washing and replacement of clothes due to disability, I won’t be able to go out and the glasses I have to replace every 6 months. I would have to choose between eating wheat free food, (if I don’t, I become ill) going out or replacing the shoes that I’ve just wrecked because of how I walk. That is not right.

PIP should be based on the amount of help that’s needed and not the type. That could potentially mean that someone who needs a lot of care gets less money than someone who doesn’t need as much help. That is not right.

For me, DLA means I can pay for taxis to take me places. Parents can’t always take me and public transport doesn’t always go near my destination. (can’t always manage on public transport) DLA also means being able to pay for things the NHS won’t pay for – like the medication that costs me £11 a time, the tinted glasses with prisms that only last me 6-12 months and the visual aids I need.
If I lost my DLA, I would have to choose between what means the least to me. That could mean not having a social life, NHS having to provide more treatment for me, (therefore, costing more than £39.10 a week) being stuck inside all day or having to go without other things I need.

It is wrong that the Government are considering removing benefits from the people who need them most. They claim that they’re going to give sickness / disability benefits to people most in need – that sounds like the ones who are at deaths’ door. That is not right.

They are considering removing the mobility component from people who can mobilise. Many use their DLA mobility to lease / buy a car / wheelchair. If they don’t have their chair or car, how are they expected to go out? They may also lose their bus pass and blue badge. These people will be left housebound and they won’t be able to work. That would cost more money – because the Government would have to pay sickness benefits, as well as money for housing and council tax. What about those who use their mobility money to pay for a wheelchair? Or is someone willing to pay for that?

There’s nothing (aside from going toilet) about night time care needs. Or is going into spasm due to staying in the same position all night (because you can’t fund someone for overnight care due to loss of DLA) acceptable? It’s just going to cost the NHS more and more money – that isn’t right.

In order to qualify for ILF (independent living fund) one criteria is high rate care – what happens to those people?

All in all, this is wrong. Why constantly target the disabled people? Why not those who actually cheat the system? First, you take away IB, put those people on a benefit that pretty much requires them to be dead in order to qualify, you limit that benefit for a year and now you want to take away their DLA, their adapted car, their blue badge, their freedom. What next? Their life?
Written evidence submitted by OXFORDSHIRE WELFARE RIGHTS (PIP 16)

SUMMARY

- PIP must be viewed in terms of an over riding aim to achieve expenditure reduction and not to meeting the future needs of disabled people.

- PIP will replace DLA with an equally complex benefit.

- The proposed assessment process for PIP is likely to raise very similar issues to those concerning the WCA highlighted in the committee’s Sixth Report.

- Experience of the PCA and WCA suggests Atos will not be a suitable provider.

- The proposed review process will replicate the WCA ‘revolving door’ of frequent re-assessment, disallowance and successful appeal.

- Evidence gathering processes under PIP processes must avoid the current inadequacies within the DLA and WCA procedures.

- Proposed changes to the review and appeal provisions will result in increased delay for individuals and further complication, rather than simplification, of the process.

- The failure to address provision for children and interaction with Carer’s Allowance at an early stage is a significant omission.

- The proposed extension of the qualifying period to six months is not justified. Provision must be made that enables an individual to qualify for PIP before the qualifying period has expired where the onset of need is rapid or sudden.

- The arguments made for the reform of DLA are not justified.

Oxfordshire Welfare Rights (OWR) provides ‘second tier’ advice in social security law including tribunal representation, a telephone consultancy service for other agencies and training courses. OWR has represented claimants at tribunal hearings since the introduction of Disability Living Allowance in 1992.

OWR advises individuals across the full range of conditions and disabilities and does not ‘cherry pick’ the individuals it represents. Only rarely is it necessary to advise an individual, on the basis of the evidence, that their appeal has no merit.
OWR has a success rate at tribunal hearings in DLA cases of 85%.¹

The need for DLA reform

1. Reform of DLA, and expenditure reduction are legitimate policy objectives of Government.

2. In its response to the consultation process² the DWP states:

> [...] DLA is no longer meeting the needs of a 21st Century welfare system and is not sustainable in the long term. In just eight years, the number of people receiving DLA has risen from 2.5 million to 3.2 million – an increase of 30 per cent. People are unclear about who qualifies for benefit, and awards can be inconsistent and subjective. 

   [page 10, para. 2]

3. However no explanation of why the number of people receiving DLA has increased is provided.

4. DLA was only introduced in 1992. The difference between the needs of a late 20th Century and early 21st Century welfare system is not explained.

5. We submit that the only tangible argument made for reform of DLA is:

> Reducing projected working-age expenditure by 20 per cent in 2015/16 means reducing working-age expenditure to 2009/10 levels in real terms - £11.8 billion.

   [page 3, para. 10]

6. PIP must be viewed in terms of an over-riding aim to achieve expenditure reduction and not to meeting the future needs of disabled people.

Disability Benefits

7. Crudely both DLA and PIP use a proxy test to determine how to distribute cash to individuals to spend as they wish (there is no requirement that the payment is actually used to meet specific needs identified by qualifying criteria).

8. The social security system seeks to define individual need by reference to criteria defined in law. The system attempts to fit individuals into legally

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¹ Average of annual success rate at appeals since 1992.
² Government’s response to the consultation on Disability Living Allowance reform. Cm 8051
defined boxes (rather than shape the system to meet individual need). That is always going to require a complex process.

9. A system which was truly capable of assessing and meeting individual need would be even more difficult and expensive to administer.

**Design of PIP**

*Our aim, through the introduction of Personal Independence Payment, is to make the benefit fairer, more straightforward to administer, and for it to be easier and clearer to understand.*

[page 4, para. 14]

10. OWR agrees that the qualifying conditions for DLA can be difficult to understand. However that can be said of much of the social security system. We therefore support benefit simplification.

11. Changing the name, assessment process and qualifying criteria for DLA will not, of itself, achieve the stated objective. PIP will not create 'a truly personalised benefit that evolves over time'.

12. **PIP will simply replace DLA with an equally complex benefit.**

**Proposed rates of payment**

13. Without detail of how daily living activities will be scored and how a particular score will relate to the rate of benefit payable it is not possible to comment on the impact of PIP on potential recipients or those currently in receipt of DLA.

**The proposed assessment process**

*It is intended to be a simpler, fairer, more objective and more transparent assessment of individual need.*

[page 4, para. 18]

14. The initial draft of the PIP assessment regulations suggests a process and legislative criteria very similar to the Work Capability Assessment (WCA) for Employment & Support Allowance (ESA).

15. We note the Committee’s recent report on the WCA and Incapacity Benefit migration.

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3 Personal Independence Payments: initial draft of assessment regulations. DWP. May 2011
16. OWR represents claimants at WCA appeals. **OWR has a success rate of 94% in WCA appeals.** We had a similar level of success under the Personal Capabilities Assessment (PCA).

17. Figures from the Tribunals Service\(^5\) demonstrate that there are significant problems with the application of the WCA. The percentage of WCA appeals allowed is almost the same as for DLA at 37% and 38% respectively.

18. The number of appeals allowed where the claimant was represented at the hearing increased significantly to 56% (DLA) and 67% (WCA).\(^6\)

19. Experience of the PCA and WCA suggests that the number of appeals made under PIP may be greater than under DLA.

20. PIP will not provide a simpler, fairer, more objective and more transparent assessment of individual need.

21. **The proposed assessment process for PIP is likely to raise very similar issues to those concerning the WCA as highlighted in the committee’s Sixth Report.**

22. **Experience of the PCA and WCA suggests Atos will not be a suitable provider.**

### The proposed review process

\[\ldots\ldots\text{there is not currently any systematic way of ensuring that awards remain correct.}\]

[page 4, para. 20]

23. Individual’s conditions and needs can change therefore a process by which awards can be reviewed is appropriate.

24. Such powers already exist under DLA. That they have not been used consistently or effectively merely demonstrates administrative failings within the DWP, not a failure of the DLA provisions.

25. Under the PCA/WCA individuals are re-assessed on a regular basis. OWR has referred to this process as the ‘WCA revolving door’\(^7\).

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26. It will cause unnecessary stress and delay for many individuals subject to the process and increased costs to the public purse.

27. The proposed review process will replicate the WCA ‘revolving door’ of frequent re-assessment, disallowance and successful appeal.

Evidence gathering

28. Any initiative that will enable claimants to better understand the qualifying conditions for PIP and provide appropriate information about their needs is to be welcomed.

29. There will remain a need for effective support that in many cases is independent of the DWP, to enable individuals to make a claim and provide the information required by a decision maker to determine their claim.

30. A weakness of the DLA claim process is the lack of a systematic process by which appropriate evidence from relevant persons, such as the claimants own GP, can be obtained. For example, the report form DBD370(N) GPFR sent to GPs is too general to elicit responses that address the DLA qualifying criteria relevant to the individual concerned.

31. OWR has highlighted the similar lack of a systematic procedure within the application of the WCA and the poor quality of assessments provided to DWP by Atos.  

32. Evidence gathering processes under PIP processes must avoid the current inadequacies within the DLA and WCA procedures.

Decision-making and appeals

33. Initiatives such as those established following the Harrington Review are welcomed.

34. OWR’s experience over many years of advising and representing claimants at tribunal in DLA and PCA/WCA appeals leads to our conclusion that the

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proposed process for assessing PIP will not lead to a reduction in the inconsistency of decision making. 

35. Under PIP there is unlikely to be a reduction in the number of applications for revision (‘reconsideration’) or appeal.

36. The DWP’s intention ‘to encourage individuals to contact the Department to discuss their case before entering the formal dispute process’ [page 42, para. 120] is of particular concern.

37. For such a process to achieve appropriate outcomes it will require a substantial increase in the quality of decision making. At a time of spending cuts and staff reduction it is doubtful that DWP will have the ability to apply and maintain improvement in the quality of decision making.

38. Clause 99 of the Welfare Reform Bill will require consideration of a revision before an appeal. This would return to the pre 1998 ‘two stage’ process. OWR argued that the ‘two stage’ process was not effective and led to long and unnecessary delays.

39. A requirement for individuals to enter a two stage process will lead to many people, particularly the most vulnerable, to miss deadlines, fail to pursue their challenge and have a legitimate claim refused.

40. The result will be increased delays for individuals and further complication, rather than simplification, of the process.

Children, Attendance Allowance, Carers Allowance and transitional arrangements

41. OWR disputes the assertion that “the needs of children are very different to those of adults” [page 5, para 27]. Children’s needs are as varied as those of adults. Their needs may be similar to those of adults particularly during teenage years. An individual’s needs do not change at their sixteenth birthday simply because they are no longer defined as a child for benefit purposes.

42. Under the proposed qualifying criteria for PIP a significant number of young people who may have continued to qualify for DLA after their sixteenth birthday may not qualify for PIP. This means a potentially significant reduction in income and support for the young person, their family or carer.

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9 The Social Security Act 1998 replaced the provisions of section 30 Social Security Administration Act 1992


43. Similarly, whilst it is proposed that individuals in receipt of PIP when they reach ‘pension age’ will continue to receive it, because of the differing criteria there may be some for whom a claim for Attendance Allowance would be more appropriate.

44. No detail has been provided of how PIP will interact with Carer’s Allowance.

45. No detail has been provided of any transitional provision which may be applied to individual’s affected by the introduction of PIP and the potential ‘cut off’ points at age 16 and pension age.

46. The failure to address these issues at an early stage in the design of PIP will leave many disabled people and their carers in a position of uncertainty about how the proposals will affect them. It will lead many to view PIP with suspicion.

47. A failure to address these issues at an early stage must lead to the conclusion that the introduction of PIP is driven by a ‘cuts’ agenda and not the future needs of disabled people and their carers.

The qualifying period

48. The proposed extension of the qualifying period to six months is not justified. It will particularly affect individuals, their family and carers, where the onset of need is rapid or sudden, for example due to cancer, stroke or a road traffic accident.

49. At a time when income may reduce significantly, arrangements for care etc will need to be made and significant emotional stress is experienced access to financial help through PIP and Carer’s Allowance will be denied.

50. Special provision (in addition to the ‘terminal illness’ rule) must be made to allow an individual to qualify for PIP before the qualifying period has expired where the onset of need is rapid or sudden.

CONCLUSION

51. OWR is staffed by experienced welfare rights advisers who regularly represent at tribunal hearings. They are able to interview an individual and within a period of about one hour accurately assess whether a person will qualify for DLA and which rate is appropriate.

52. OWR is able to achieve this quality of outcome because our staff have the necessary level of experience and understanding of the DLA criteria and case
law. They are able to outline those criteria clearly to individuals and ask them appropriate questions. They are able to obtain additional evidence from the claimant’s health advisers or other appropriate persons in a format that directly addresses the DLA criteria.

53. If OWR is able to achieve such a high and consistent level of outcome then DWP and Atos should be able to achieve a similarly high quality of assessments and decision-making.

54. A fundamental problem with DLA and the WCA is that Atos/DWP staff do not have the necessary knowledge and skills to apply the qualifying criteria and urgent action is required to address this.

55. We welcome a commitment to improve the provision of support to disabled people and to simplify the application and assessment process. PIP will not achieve those objectives.

56. The proposals are fundamentally flawed because:

   - PIP will be no simpler than DLA to understand or administer.
   - The proposed assessment criteria will not provide an accurate or reliable assessment of need.
   - The proposed assessment process will replicate the fundamental problems already associated with the application of the Work Capability Assessment.
   - PIP will not produce an improvement in the quality of decision making.

57. The PIP proposals will continue to cause significant concerns and uncertainty for disabled people.

58. PIP will rapidly become as discredited as the Work Capability Assessment.

August 2011
Written evidence submitted by the Muscular Dystrophy Campaign (PIP 17)

Executive summary

- We welcome the Committee’s inquiry into the proposal to replace Disability Living Allowance (DLA) with Personal Independence Payment (PIP). We have significant concerns about how a new assessment will work for people with neuromuscular conditions and about the proposal to remove the mobility component from people living in residential care and residential colleges.

- Neuromuscular conditions are a set of rare and very rare conditions affecting 71,000 people across the UK. Because neuromuscular conditions are so rare, healthcare professionals carrying out a face-to-face assessment, as seems likely to be proposed for PIP, are therefore unlikely to have come into contact with more than a handful of such patients in their careers and will have little knowledge of the conditions.

- We therefore propose a tiered assessment process, with evidence from experts, such as an individual’s consultant neurologist or neuromuscular care advisor, being given due weight and face-to-face assessments only being carried out where there is insufficient information to make a decision on eligibility for PIP.

- Similarly, as the majority of neuromuscular conditions are progressive, and in some cases life-limiting, we do not believe that regular reassessment is necessary for this group of people.

- We strongly disagree with the proposal to remove the mobility component from people in residential care and are concerned that this could have a significant impact on people in residential homes or residential colleges.

- We welcome the fact that the proposed changes do not currently apply to children and would urge full consultation on any future proposals to reform child DLA.

- We believe that the Government should reconsider how PIP applies to adults over the state pension age. Current arrangements mean that older adults with late-onset conditions often miss out on vital support.

Introduction

1. The Muscular Dystrophy Campaign represents the 71,000 people in the UK with muscular dystrophy or a related neuromuscular condition. There are more than 60 different types of muscular dystrophy and related neuromuscular conditions, many of which are low incidence, orphan conditions and indeed some are very rare and are regarded as ultra orphan. Neuromuscular conditions can be genetic or acquired and, with the exception of a couple of acquired conditions, there are no known effective treatments or cures.

2. Disability Living Allowance (DLA) is a vital benefit intended to help people meet the extra costs of their disability and, as such, is fundamental to supporting
disabled people fulfil their potential and giving them the same opportunities as others in society.

3. In our 2010 report, *The Cost of Living with Muscle Disease*¹, we found that, of the people we surveyed, over two-thirds had experienced financial difficulties as a result of living with their condition; two out of five families struggled to pay their bills due to their neuromuscular condition and four out of five families did not think that the benefits system adequately covers these costs.

4. Extra costs can arise for people with neuromuscular conditions for a number of reasons, for example through having to rely on wheelchair-accessible taxis in areas where public transport is not accessible, or because of the higher electricity bills which can result from specialist equipment such as powered wheelchairs, ceiling hoists and through-floor lifts.

5. Whilst reviewing DLA is welcomed, the Personal Independence Payment (PIP) which currently is proposed as the replacement benefit, must continue to allow people with neuromuscular conditions to meet these extra costs and enable them to live the lives they want to. With the Government aiming for a ‘reduction target’ of 20% in DLA payments, as set out in the Budget report in June 2010², we are concerned that some people’s needs may not be recognised, meaning some may miss out on the vital support they need to live an independent life.

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**Indra has a form of muscular dystrophy and due to her progressive muscle wasting condition, she has considerable mobility issues. She has good and bad days; some days she can manage her needs but on other days, due to her muscle strength and fatigue, she requires assistance with almost everything – walking, getting up from a sitting position, cooking, washing and personal care. During bad periods, she can go for four weeks without being able to leave the house. She has recently been reassessed for DLA and has been told she is no longer entitled to the care component and will have her mobility component downgraded.**

The newly proposed assessment process must have a level of flexibility to allow for people like Indra whose needs may not always be immediately apparent. Indra desperately requires this assistance to meet the extra cost of living with her disability; the thought of losing this support has put her under severe stress and consequently she was recently taken to hospital with panic attacks.

The Muscular Dystrophy Campaign is now working with Indra to get the support to which she is entitled, allowing her to live a full, independent life.

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**The design of the PIP assessment**

6. At the moment, potential claimants are required to fill in a comprehensive form outlining the impact of their disability on their day-to-day life in order to apply for DLA. Some people may also be required to undergo a face-to-face assessment with a healthcare professional if further clarity is required before making a decision regarding eligibility for the benefit.

7. Claimants are also able to ask someone who knows them to complete the section on the DLA claim form confirming their statements – most often their doctor or another healthcare professional – although they are not required to do this.³

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8. Because of the range of neuromuscular conditions, the severity of conditions and how they affect individuals varies greatly from person to person. However, the majority are progressive, causing the muscles to gradually weaken and waste over time, affecting mobility and leading to some sort of disability. Some conditions, such as Duchenne muscular dystrophy, are severe and life-limiting; those affected will generally require a wheelchair by the age of twelve and will often not live beyond early adulthood.

9. In their response to the public consultation on DLA reform, the Government state that they intend the assessment for the daily living component of PIP will focus on “those key everyday activities which are essential to enabling participation and independence”.4

10. It is currently proposed that this part of the assessment will focus on activities such as feeding, toileting and dressing. Whilst these activities are vital to daily living, we believe that looking at these activities in isolation will not enable PIP to achieve its stated intention of targeting supporting “at individuals who require the most assistance to live full, active and independent lives”.5 People with complex needs arising from their neuromuscular condition may well require different types of support, for example to access education or to get involved in their local community.

11. It has been proposed that some aids and adaptations should be taken into account when assessing eligibility for PIP. We would have concerns about this approach as the provision of equipment, such as a wheelchair, does not remove all of the barriers to accessing mainstream society or the additional costs of a disability. Wheelchair users, for example, will still often be reliant on taxis as much public transport remains inaccessible and 50% of the UK’s trains and stations’ facilities for disabled people were not up to scratch when investigated as part of the End of the Line transport report in 2009.6

12. We would be highly concerned if the criteria for PIP were to mirror those currently being used to assess eligibility for Employment and Support Allowance. The 2011 descriptors now assess whether an individual is able to mobilise 50 metres, as opposed being able to walk 50 metres. In practice, this means that if an individual can self propel a manual wheelchair for 50 metres on level ground and none of the other descriptors apply they will be found fit for work, which fails to take into account many of the practical barriers to work faced by a manual wheelchair user.

13. We would strongly recommend that issues such as these are given careful consideration and would suggest that aids such as wheelchairs should not be taken into account in the PIP assessment.

The delivery of the PIP assessment
14. The public consultation on DLA reform talks about introducing a new objective assessment, most likely a face-to-face assessment carried out by a healthcare professional. Whilst this may be appropriate in some cases, many people with muscle disease will be severely disabled by their condition and it may not be the most effective use of limited financial resource to require them to attend a face-to-face assessment.

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5 Ibid, p. 23
6 http://www.muscular-dystrophy.org/assets/0001/4049/Trailblazers_-_End_of_the_Line.pdf
15. Instead, we propose that there be a tiered assessment process. For many individuals with neuromuscular conditions, completing a comprehensive form similar to that used at the moment and submitting supporting evidence from a healthcare professional who knows them well – for example a consultant neurologist or neuromuscular care advisor – should be sufficient to adequately assess their entitlement to the benefit. Only when this approach does not provide enough information to assess entitlement should someone be invited for a face-to-face assessment.

16. Similarly, for individuals with severe, progressive and life-limiting conditions such as Duchenne muscular dystrophy, it makes little sense for them to be given the benefit for a fixed period of time as their condition will only worsen. In these cases, indefinite entitlement should be retained.

17. Finally, any new assessment for PIP must take into account the lessons learnt from Professor Harrington’s first annual review of the Work Capability Assessment (WCA) and the second review which is currently being carried out. The first review7 highlighted a number of problems with the WCA, including the fact that Jobcentre Plus Decision Makers “typically ‘rubber stamp’ the advice provided through the Atos assessment”. For rare conditions such as muscular dystrophy, the assessor is very unlikely to have sufficient knowledge to adequately assess the full range of an individual’s needs: it is therefore vital that evidence from experts, such as a neuromuscular care advisor, is given due weight during the assessment process.

Elliot and his twin brother have limb girdle muscular dystrophy - a progressive muscle wasting condition for which there is no cure and which can be severely disabling. Both experience extensive mobility impairments and require similar levels of support. However when assessed for DLA, Eliot’s specialist needs were misunderstood and he was denied this support whilst his brother had no issue in receiving this benefit.

Elliot needs were a clear fit for the DLA criteria: he struggles to walk, dress, wash, cook or undertake his personal care independently. Because those assessing him did not understand the implications of his condition, he struggled for many months without this financial assistance. The Muscular Dystrophy Campaign has since worked with Elliot and he now receives the higher rate of both the mobility and care components of DLA.

The mobility component of PIP for people in residential care and colleges
18. The Welfare Reform Bill 2011 currently gives the power to enact regulations removing the mobility component of PIP from people living in residential care. We strongly disagree with this proposal and are concerned that this could have a significant impact on people in residential homes or residential colleges.

19. Residential colleges may only provide transport for the start and end of term, with no extra provision for visits at weekends, or for the young person when they’re at home during the holidays. Without the mobility component, families will be left without this vital support to help meet transport costs, and furthermore, be ineligible for an adapted vehicle through the Motability scheme.

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20. Many families will not be able to fund their own adapted vehicle, leaving them unable to visit their child at school, and take them out for visits, or even back to the family home. During the holidays, young people may end up stuck as a prisoner in their own home, unable to get out and take part in leisure activities, or even attend essential hospital appointments.

18 year old Daniel Warren is affected by Duchenne muscular dystrophy, a severely disabling condition. He is a powered wheelchair user and has very limited mobility in his arms and hands. Daniel is currently studying at a residential college, a round trip of some 250 miles away from his home, and is transported to and from school by his mother Philippa, in their adapted van. During his holidays, Philippa transports Daniel to his regular hospital appointments, to meet his friends, and visit family, including his baby niece. Next year, Daniel is due to leave college, and move into a residential care unit. Under the government’s proposals, the family would lose their adapted vehicle, and all support for transport costs, preventing Daniel from taking part in full family life while he is at college, and potentially denying him his dream of living independently.

21. This proposal will also affect adults of all ages with severe disabilities who are supported by the state to live in residential care – including many young adults living independently for the first time who rightly expect to live full and independent lives.

22. Restricting their access to Motability or financial support for paying for public transport, many disabled adults will be unable to retain voluntary employment (which is not covered by the Access to Work scheme), or simply to visit family and friends.

23. By arguing that disabled people in care homes should just make do with the transport provided by the home (where it exists) the government is acting in contradiction of the objectives behind the personalisation of social care, Direct Payments and Personal Budgets, where disabled people are given the choice and resources to manage their own lives. It is hard to see how this proposal can co-exist with the principle stated in A Vision for Adult Social Care: Capable Communities and Active Citizens: “Personalisation: individuals not institutions take control of their care.”

How DLA/PIP should apply to children and people over the state pension age

24. During the second reading of the Welfare Reform Bill 2011, when asked about the impact of DLA reform on children, Iain Duncan Smith said: "We are consulting on that. However, this is going to be done later on, so we will have plenty of time to hear many more representations concerning children before we make any decisions."

25. We welcome the fact that these changes do not currently apply to children. We would have concerns about subjecting young people and their families to face-to-face assessments, particularly when they may be dealing with the impact of receiving a diagnosis of a life-limiting condition and struggling to access the specialist health care they need.

26. We would urge the Government to consult fully before making any changes to child DLA.

8 DH A Vision for Adult Social Care (November 2010)
9 http://www.publications.parliament.uk/pa/cm201011/cmhansrd/cm110309/debtext/110309-0002.htm
27. As current proposals stand, only adults of working age will be able to make a new claim for PIP. This is also true of DLA and can have a significant impact on the lives of older adults with neuromuscular conditions, particularly those who develop one of the conditions which typically manifests itself in later life; for example Inclusion Body Myositis.

28. These rules can deny older adults the opportunity to continue to live an independent and active life. For example, Doug Sibley from Eastbourne is affected by FSH muscular dystrophy, and told us that not being able to claim DLA is: “Like kicking you when you’re down. The rules do not consider the fact that you want to remain active.”10

29. We therefore strongly believe that adults over the state pension age should be able to make a new claim for PIP.

August 2011

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Written evidence submitted by Citizens Advice Scotland (PIP 18)

Introduction
1. Citizens Advice Scotland (CAS) is the umbrella organisation for Scotland’s network of 81 Citizens Advice Bureau (CAB) offices. These bureaux deliver frontline advice services through at 261 service points across the country, from the city centres of Glasgow and Edinburgh to the Highlands, Islands and rural Borders communities.

2. CAS welcomes the opportunity to respond to the Work and Pensions committee consultation on the proposal to replace DLA with Personal Independence Payment (PIP).

3. Citizens advice bureaux provide advice to a significant number of clients who are unable to work because of ill health or disability – in 2009/10, around one in six Scottish CAB clients were in this category. In 2006, CAS carried out research on the costs of illness and disability for CAB clients claiming Incapacity Benefit (IB) and/or Disability Living Allowance (DLA)¹, which highlighted the vulnerability of this client group. The report found:

   Just over half reported a physical disability
   Over a third reported a mental health condition
   A quarter had multiple health conditions
   Eighty per cent said that their condition was fluctuating or getting worse
   Just under a third had a monthly household income of less than £400
   Clients in this group were five times more likely than the general population to be in financial difficulty.

4. During 2009/10, citizens advice bureaux in Scotland dealt with 188,969 new benefit issues for clients – just over a third of all issues brought to bureaux. That is over 500 new benefit issues for every day of the year. More than 55,000 of these new problems were issues related to the various sickness and disability benefits.

5. More than 37,500 of those enquiries concerned Disability Living Allowance (DLA) – a fifth of benefit issues and nearly 1 in 15 of all new issues brought to bureaux.

6. CAB provide advice on many areas of the benefit process, including advising on entitlement, helping with the claiming process, advising and providing representation in appeals, and dealing with payment and administration problems.

¹ Paying the Price: The real costs of illness and disability for CAB clients (July 2006)
Consultation on the proposal to replace DLA with Personal Independence Payment

Question 1 – How well understood DLA is; why the DLA caseload and expenditure has increased

7. The majority of DLA clients understand that DLA is a non-means-tested benefit that can be used as the individual chooses, in recognition of the extra costs incurred by disabled people due to their disability.

8. The process of claiming DLA is a complex maze for many clients, and the primary reason for DLA being the biggest single issue bureaux deal with. Last year CAB dealt with over 37,500 enquiries concerning DLA. The majority of these enquiries relate to entitlement and processing issues by the Department for Work and Pensions.

9. Many clients who apply for DLA struggle to access and claim the benefits they are entitled to. This can be due to complexity, poor information and a lack of awareness of DLA entitlement.

10. Research by Citizens Advice Scotland in 2006 evidenced that 40% of CAB DLA clients struggle with complexity of the claim forms and 14% needed help and support in making their claim\(^2\). This can lead to financial hardship for many clients and their families.

A West of Scotland CAB reports of a client who suffered from chronic fatigue syndrome and wanted to apply for DLA. He found the form very confusing and did not have the energy to fill it in himself. Additionally, he was not sure what to write and stated he would have given up after 30 minutes. Even with the bureau adviser’s help, it took over two hours to complete the form.

A West of Scotland CAB reports of a client who had been awarded high rate DLA mobility for life fifteen years ago. The client recently had a heart attack which meant he needed further care. The client was scared if he re-applied for DLA hoping to be awarded the care component, his mobility component might be removed.

A West of Scotland CAB reports of a client who couldn’t understand the DLA application form and the accompanying information notes. The client had been struggling for over two months to fill in the form. He had come to the bureau to assist him to fill it in. The client had been accessing crisis loans and borrowing off friends and family to survive. It wasn’t until he was told by a friend that a citizens advice bureau could help him with his forms he began to think about trying to claim again.

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\(^2\) Paying the Price: The real costs of illness and disability for CAB clients, CAS, 2006
A North of Scotland CAB reports of a client who suffered from Paranoid Schizophrenia and was given a lifetime award of DLA. The client was then told by DWP he would have to undertake a review even though he was receiving a lifetime award. The client didn’t respond to the review notice and consequently has had his benefits stopped. The client was enquiring about how to claim a crisis loan as he had no money. The lack of information concerning his entitlement and the review had meant the client was very confused.

11. The increase in the number of DLA claimants can largely be explained by the overall increase in population since 1992 and the fact that the UK has an ageing population. Furthermore, an individual must be under 65 to claim DLA for the first time, but once s/he has started receiving it s/he can continue to do so regardless of age. This means that in 1992, all claimants were under 65 – but now there will be claimants up to the age of 84.

12. This has meant more clients visiting bureaux in recent years who are confused about their DLA entitlement and suffering due to administration/processing issues. Bureaux across Scotland support clients to understand their DLA claim and ensure they receive what they are entitled to. In 2010/11, using a snapshot of 4296 DLA clients, bureaux ensured a client financial gain of £11,376,065 or £2648 for each of these clients.

13. The number of DLA claimants receiving bureau advice and support has resulted in an increased understanding and awareness of DLA entitlement. The increase in population has meant more people claiming what they are entitled to and has resulted in the increased expenditure on DLA.

Question 2 – 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

14. The Government’s intention is to reduce expenditure on DLA by over £1 billion a year by introducing a new benefit PIP. The objective will only be achieved by a significant reduction in the number of claimants.

15. A significant majority of CAB DLA clients are unemployed and just over half have significant debts. If the UK government make disability benefits available to only those whose need is the greatest, it will leave many unemployed disabled clients without vital income. These clients will be left in poverty trying to fund a disability and the associated costs if DLA is reserved only for those with the greatest need to claim.

16. In 2006, almost three quarters of CAB DLA clients stated that their disability had caused them to stop working, and for 12% it had prevented them from ever being employed. This translates to 84% of DLA clients solely relying on benefits to live their life and has left many of these clients in financial hardship and living in poverty.

A North of Scotland CAB reports of a client who had worked as a painter and decorator for over twenty years. The client had recently become disabled and had to stop working, relying on DLA and other benefits to support himself. The client is struggling to make ends meet and can’t afford to turn on the heating. The lack of heating is affecting his disability even more. A West of Scotland CAB reports of a client who had two strokes and had to leave his job and claim DLA. The client came to bureau to see if he could access any other benefits as he

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3 HM Government, *Budget 2010*, Table 2.1 Citizens Advice Scotland 6 A response to the consultation on DLA Reform

4 Paying the Price: The real costs of illness and disability for CAB clients, CAS, 2006
needs more money to buy food. The client had been unable to eat properly for over two weeks and had been relying on food parcels from the Salvation Army.

17. DLA clients’ inability to work has left many struggling on low incomes and in poverty. In fact, CAB DLA clients are five times more likely as the general population to be in some form of financial difficulty. DLA is a tax free benefit for disabled children and adults to cover extra costs incurred as a result of a disability. Unfortunately, many of our clients’ independence suffers because DLA does not cover these extra costs.

18. Over 50% of CAB DLA clients have outstanding debts, most commonly in relation to credit cards and Council Tax arrears. Around 40% of CAB DLA clients have debts over £5000. Many CAB DLA clients juggle their finances to cope with their debt, while others try to reduce expenditure or go without essentials to cope with their debts.

An East of Scotland CAB reports of a client who was appealing a reduction in his DLA which had meant that his Income Support had been stopped. The client had got into debt on credit cards to pay utility costs. The client also had rent arrears which meant he was facing being evicted and homelessness.

A West of Scotland CAB reports of a client who has had her Employment and Support Allowance (ESA) appeal rejected and is currently in the process of dealing with a DLA appeal. The client has no money, but has taken out a loan with a doorstep lender and can’t afford to make her repayments. The client wanted to claim a crisis loan but cannot get through by telephone and has had calls that have had her waiting up to two hours. The client is now feeling suicidal.

19. A solution to the problem of CAB DLA clients living in financial hardship and poverty would be to uprate the components of disability living allowance to reflect the inability to work and the extra costs of living independently. The DWP’s own statistics show that the poverty rate of disabled people is higher – without even attempting to take account of these costs. Research shows that the rates of benefit are not adequate to meet the costs that many disabled people face and further changes could also act as barrier to independence.

Impact of having only two rates of PIP
20. There will be two components of PIP. These will be “daily living” and “mobility”; both will be paid at one of two rates – “standard” or “enhanced”. The assessment to decide these will be points-based, focussing on certain fundamental activities, with a number of descriptors for each one.

21. The activities to be assessed for PIP are very limited in scope which will result in a loss of entitlement for those who have less severe disabilities, or those who have adapted well. No provision is present to give special recognition to night time care needs. This is a departure from the current structure of the DLA care component.

22. Many who require „continual supervision” and receive middle rate care under DLA regulations will find it difficult to qualify under the new criteria, which only recognises intervention from another person in the form of „assistance” or „prompting”. As an example, claimants with uncontrolled epilepsy who have regular seizures may not satisfy the medication and monitoring health condition descriptors as drafted.

5 Households Below Average Income: an analysis of the income distribution, DWP, 2009
6 Disability Poverty in the UK, Save the Children, 2008
23. Many vulnerable people will be left in poverty and financial exclusion trying to fund a disability and the associated costs if DLA is reserved only for those with the greatest need to claim.

**Question 3 – The extent to which overlaps in funding exist, particularly with local authority and NHS funding**

24. DLA is a benefit paid to people in recognition of the additional mobility and care costs of people who have a disability or illness. It is intended to help with the additional costs associated with illness or disability. However, CAS evidence shows that the current benefit rate does not suffice to cover extra costs of living with a disability. These extra costs are currently not funded by local authority or NHS funding.7

25. The most common extra needs are prescription charges, other chemist items, transport and mobility related needs, energy costs, aids and adaptations, dental costs and childcare.

A North of Scotland CAB reports of a client who is claiming DLA. The client requires medication for his disability which costs over £50 a month. The client cannot afford these prescription charges from the money he receives from his DLA. The client is in a desperate position where he can’t afford medicine to improve his condition.

An East of Scotland CAB reports of a client who suffers from MS who volunteers for the Salvation Army. The client’s travel costs have recently increased and he can no longer afford to get a taxi to and from his place of volunteering. The client’s DLA doesn’t cover the increased costs and has left him without the opportunity to volunteer and socialise.

26. The removal of DLA financial support will lead to increased reliance on social care and other local authority services. This extra burden on local authorities will be felt disproportionately in Scotland where many local authorities take disability benefits – such as the care component of DLA - into account when they are calculating care charges. As DLA is reduced, so will the available income of service users and, in turn, the amount that local authorities are able to charge for care packages. This will not be the case to the same extent in England, where the Department of Health has issued guidance on fair charging of disabled people.8

27. Furthermore, the mobility component of DLA is often used to informally subsidise, upgrade or repair publically provided wheelchairs, aids and adaptations. If DLA (or its equivalent) is removed from 20% of claimants, then this burden will fall on local authority and the NHS.

**Question 4 - Should some health conditions or impairments mean an automatic entitlement to the benefit**

28. CAS recommends consulting with third sector health organisations and healthcare professionals to decide what these exemptions should be.

**Question 5 - The implications of a six month qualifying period**

29. The extension of the qualification period will act to exclude disabled people at the very time when adequate financial support can make the most positive difference. Government statistics suggest, the additional cost of six months of disability could range from £43.44 to

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7 Paying the Price: The real costs of illness and disability for CAB clients, CAS, 2006

8 Rapid Response Report on Disability Related Expenditure, Capability Scotland, February 2011
£9,0789. Lack of any support with these costs limits the ability of thousands of people to live independently and increases their financial hardship.

**Question 6 - 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**

30. 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 respect10. The Harrington Review recommendations for changes to WCA are enthusiastically accepted in an ESA context. Lessons need to be learnt from this review before any PIP assessment is introduced.

31. Citizens Advice Bureaux have reported a number of clients with fluctuating conditions who were found fit for work after their work capability assessment (WCA) when claiming ESA. Many of these clients voiced their frustration that the WCA did not reflect their capability on an average day. CAB have seen a number of clients with varying conditions, such as mental health issues, Multiple Sclerosis and Parkinson’s Disease, who have been found fit for work after being assessed on a „good day“ for their condition. It is essential that the new DLA medical assessment is able to take into account both the „good days“ and the many other „bad days“ that a claimant may experience.

A West of Scotland CAB reports of a client who suffers from Paranoid Schizophrenia who was assessed fit for work. The client’s condition is variable and can change on a weekly basis and he often ends up sectioned. On the day of his Employment and Support Allowance Work Capability Assessment, the client was having one of his better days and was found fit for work. No supporting evidence was taken into account from his healthcare professionals.

32. Any one-off new medical assessment for DLA may be inappropriate for clients who have medically diagnosed fluctuating conditions. For these claimants, it is fundamentally important that emphasis is placed on supporting medical evidence from GP’s, consultants and other healthcare professionals. These healthcare professionals are likely to have a much better impression of the capabilities of their patients over an extended period of time.

33. The new DLA medical assessment must be designed to assess the true disability of a claimant with a fluctuating condition. The medical assessment must be flexible enough to allow substantial input from a claimant, especially where a fluctuating condition has been diagnosed. This would ensure that claimants feel that their condition was accurately assessed.

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10 An independent review of the Work Capability Assessment, Harrington, 2010
Question 7 - 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

34. A number of clients have complained that their supporting medical evidence has been ignored by DWP decision makers who have effectively "rubber stamped" the recommendation from the WCA as part of their ESA assessment. This medical evidence is then often used to successfully appeal the decision. The Harrington Review found that decision makers follow the advice of the medical assessors in 98% of cases. We strongly support Professor Harrington's recommendation that the DWP decision maker take a far more active role in making decisions based on both the assessment and the supporting medical evidence. These recommendations should be an integral part of any PIP assessment.

Question 8 - The extent to which PIP will act as a gateway to other benefits

35. DLA has proved extremely useful in providing access to other services and entitlements for many CAB DLA clients. CAS would like to see these passporting/gatekeeping arrangements remain under PIP.

36. As PIP will not be devolved to the Scottish Parliament, this legislation will impact on claimants in Scotland in different ways due to its interaction with devolved matters, principally health and social care. In Scotland local authorities are able to include DLA care component in financial assessments for non-residential care services. Claimants in residential care or hospital already have their entitlement to the care component withdrawn.

Question 9 - How DLA/PIP should be applied to children and people over the state pension age

37. CAS would have serious concerns if children had to undertake a medical assessment. It is unclear whether that would happen under the new benefit PIP. Additionally, it is unclear how children will be assessed if there is not a medical assessment. CAS suggests there needs to be further consultation on this issue.

38. The recent report on the importance of the early years of a child's life for future outcomes evidences the long term benefits and financial savings that would result from making it easier for young children to qualify for the new benefit PIP. This is not to suggest that older children do not require the same support

39. The communication by government on this matter has remained opaque. CAS recommends that the Work and Pensions committee provides clarity on whether PIP will apply to under 16s and those over 65 or not.

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11 Monitoring Poverty and Social Exclusion, Joseph Rowntree Foundation, 2010
Question 10 - The steps DWP needs to take to ensure that its reform proposals are clearly and effectively communicated to claimants and the general public and transitional arrangements

40. If the change from DLA to PIP is not a smooth transition and the application process and new medical assessment are not fit for purpose, bureaux across Scotland will see a significant increase in the numbers needing advice on disability benefits. Last year CAB in Scotland reported a 50% increase in sickness benefits enquiries. The vast majority of this increase was due to the change from Incapacity Benefit to Employment and Support Allowance.

41. To minimise this impact it is important that correct signposting to advice is available. Also all advice given by DWP advisers should be reviewed to ensure accuracy. It is important that claimants are advised to apply for the correct benefit when PIP is introduced. CAB report of the stress and financial hardship caused to our clients when wrong advice is given by DWP on which DLA component they are entitled to.

42. The impact of a poor transition from DLA to PIP will not solely be felt by DLA claimants but advice agencies as well. To cope with the transition and the increase of numbers needing signposting and direct advice, advice services would need increased funding. This would ensure a smoother transition and give advice services the capacity to deal with many extra enquiries generated by these changes.

August 2011
The North West Mental Health and Welfare Rights Group is a group of Welfare Rights Advisers, from Sheffield to Liverpool, including Local Authorities, CABx, Voluntary Agency’s, Health Trusts, Housing Associations, who meet regularly to discuss issues pertinent to benefit claimants with mental health issues. The aim of the group is to share knowledge, information and good working practices in the specialist area of Social Security Benefits and Mental Health.

This submission addresses the proposals for PIP from a mental health perspective only as this is the area of our expertise. It focuses on the issues regarding the implications of a reduction in expenditure and the PIP criteria and assessment for mental health conditions and fluctuating conditions. It has been compiled and agreed by the group, with some of the points taken from our response to Professor Harrington’s current call for evidence for his Year 2 Independent review of Employment & Support Allowance (ESA) as there are overlaps between the proposed process for PIP and the current process for ESA.

1. IMPLICATIONS OF A REDUCTION IN EXPENDITURE
1.1 PIP criteria should still recognise that a person with mental health problems may only be stable due to receiving a high level of support from engaging with Mental Health Services and receiving treatment, complying with medication etc, all of which are aided at present by DLA payments to cover the extra expenses such as attending appointments, telephoning support workers, paying for prescriptions and removal of which could lead to instability, hospital admissions and increased demand for Mental Health Services. This has already been seen by the introduction of new criteria for ESA where Community Mental Health Team (CMHT) Social Workers and Community Nurses are reporting increasing stress amongst their clients with a knock on effect on the time they can spend on therapeutic input rather than having to reassure their clients, help complete forms, help attend assessments, help with appeals etc. The CMHT’s report a huge impact on their time resources as all these actions take much longer with someone with a severe mental illness and is reversing the progress they have made in improving their clients mental health.

PROPOSAL: PIP to continue to meet needs of people with mental health problems in order to help maintain this client group living in the community.

1.2 Improvements in mental health conditions are not as clear cut as improvements in physical conditions. It is very difficult to assess when mental health conditions change as these can be variable and fluctuating, or a claimant may stop taking their medication as they feel ‘better’ or their can be a deterioration after a period of stability. Lack of insight or delusions may cause someone to report positive changes when there are none, or report stability in their condition despite a high level of support required to maintain this. People with paranoia and difficulty dealing with officials may avoid contact altogether or people who lack mental capacity or who have cognitive impairment may not realise the need to report changes in their condition. Where there is an improvement in a mental health condition there is always a risk of a relapse, especially where the person is under stress which can be caused by loss of support, loss of income.

PROPOSAL: run on period of PIP for 6mths to ensure sustained improvement, and no sanctions under PIP which would be unreasonable and discriminatory with the threat of fraud a deterrent to claiming benefit at all.

2. PIP CRITERIA
2.1 Currently people with moderate mental health problems often meet the criteria for the lowest rates of both components of DLA due to difficulty going to unknown places, inability to cook a meal, look after self. If these lower rates are removed, or the criteria changed so this client group no longer qualifies, the knock on effect could be great with deterioration in diet, self neglect, withdrawal from community and services, ceasing medication and hospital admission. These lower rates are therefore important in maintaining people with mental health issues in the community, with limited impact on local/support services.
Example:
SS has anxiety, depression and previous alcohol use. Recently discharged from 24hr Supported Accommodation after 2 years. In order to remain in community and maintain self care and alcohol abstinence needs to return to Support Group Meetings weekly, attend Alcohol Services for counselling and have help from friend for meals; all aided by DLA award of lower rate mobility and lowest rate care component.

PROPOSAL: PIP to continue to offer lower awards for claimants with moderate mental health problems.

2.2 For people who have agoraphobia, social phobia, severe anxiety, paranoia etc assistance is needed to go out and engage with the community and undertake leisure activities such as visits to library, leisure centre, church which they would not be able to do on their own. Without the extra support from the lower rate mobility component this client group would become more socially isolated, withdrawn and excluded from the community. PROPOSAL: PIP to continue to provide support to claimants with problems going out doors, widening the proposed ‘planning and following a journey’ to include social engagement.

2.3 The route to higher rate mobility component for people with mental health problems under SMI (severe mental impairment) is very restrictive and complex: ‘receipt of highest rate care component and suffer from a state of arrested development or incomplete physical development of the brain, which results in severe impairment of intelligence and social functioning and exhibit disruptive behaviour which is extreme and regularly require another person to intervene and physically restrain to prevent causing physical injury to self or another or damage to property and behaviour is so unpredictable that require another person to be present and watch over when ever awake’. Few people either understand or meet this criteria, despite someone with a severe mental health problem (schizophrenia, psychosis, paranoia, severe anxiety) having the same effect as a severe physical problem in causing them to be virtually housebound, or requiring the same expenditure on taxis to get around. PROPOSAL: PIP to ensure equal access to mobility component for claimants with both physical and mental health problems

2.4 It appears that the proposed criteria for PIP give a low score to managing treatment and medication. This is relevant to claimants with mental health problems as the ‘revolving door syndrome’ of repeat hospital admissions is well established where someone feels better, stops taking their medication, their health then deteriorates causing an admission to hospital where their medication is stabilised and they are discharged, for the cycle to start again. Monitoring of medication compliance is therefore very important to prevent these repeat admissions.

Example:
JB has schizophrenia with little insight and no understanding he needs treatment to keep him well. He lives in supported accommodation and his mother, support worker and Community Mental Health Nurse visit regularly to ensure he takes his medication, without which his mental health deteriorates rapidly requiring urgent hospital admission. Prior to this support JB had repeat admissions due to grandiose ideas that he could fly, nothing could hurt him such as cars when crossing the road and therefore had no awareness of danger.

PROPOSAL: PIP to allocate a high score for managing treatment and medication

2.5 The proposed criteria for PIP do not cover the need of people with severe mental health problems for supervision. This is a significant area for people who experience self harm, suicidal tendencies, psychosis, severe self neglect, lack of insight, lack of awareness when condition is deteriorating, risk to others, impulsive behaviour, grandiose ideas, eating disorders etc, all of which demonstrate a high level of need and all of which adversely affect a person’s ability to live independently. At present one route to middle rate care component of DLA is due to a need for ‘continual supervision throughout the day in order to avoid substantial danger to self or others’ and is crucial to many people with mental health
problems to ensure they receive the support they need, especially as many with these
difficulties live on their own, estranged from their families and friends due to the severe and
demanding nature of their ill health

Example:
RW has recurrent depressive disorder with psychotic features (voices
which tell him people are talking about him and he needs to hurt
them). Police have been involved and he is treated by Psychiatrist
and CMHT regularly, with high doses of anti-psychotic medication.
Family have disowned him due to his behaviour and he avoids his
friends and other people. Following appeal DLA awarded at middle
rate care component for supervision needs.

PROPOSAL: PIP criteria to include supervision needs

2.6 The proposed criteria for PIP do not seem to cover night time needs. For people with
mental health problems this is particularly relevant as their days and nights can merge due
to chaotic life style, effect of medications, paranoia of people during the day. Mental health
problems such as severe anxiety, psychosis, self harm can all happen day or night without
distinction causing similar difficulties whatever time they occur. Someone with associated
sleep problems may be up and about at night trying to cook, leaving the gas fire on,
wandering about and needing supervision during this time as much as during the day time.

Example:
HR has paranoid schizophrenia with command hallucinations.
Community Mental Health Assertive Outreach Team involved as does not
have any insight into condition and does not engage with services.
Regular admissions to hospital when ceases taking medication eg 3
times in 1 year. Can stay in bed all day, get up at night due to his voices
telling him to, when tries to leave the house, leaves cooker on, lets bath
overflow. Nil DLA award changed to high rate care component at appeal
for day and night supervision needs.

PROPOSAL: PIP criteria to include night time needs.

3. CLAIM FORM
3.1 The current DLA claim form is difficult for claimants with mental health problems to
complete due to:
- the mental health questions are not clear with the focus of each question being on
physical problems
- not always obvious what information is being asked for and is relevant for mental
health problems
- questions do not address fluctuating conditions such as bi-polar disorder which can
involve severe low and high moods within the period of a day, or over a number of
months, the answers therefore given being dependent on what part of this cycle is
being experienced at the time
- many people with mental health conditions live alone / have no assistance / do not
think they have ‘mobility’ problems and so assume they will not qualify for DLA
leading to under claiming by this client group.

PROPOSAL: PIP claim form to be clear and user-friendly in addressing mental health issues
and to include a diary format covering a period of time to address fluctuating conditions

4. ASSESSMENTS
4.1 For claimants with a mental health problem the face-to-face assessment process
currently used for ESA (which is similar to that proposed for PIP) is more intimidating, with
many having difficulty getting to medical centres outside their area, which are often very
busy, with long waiting times to be seen, causing a knock on effect on their mental health
due to the associated stresses and pressures. This can lead to failure to attend (FTA)
assessments, which is currently an increasing problem for people with mental health
problems claiming ESA as their benefit is stopped after 2 FTA’s despite evidence of ‘good
cause’ such as no motivation to open letters, agoraphobia, severe anxiety, hallucinations,
which is then often accepted at appeal.

Example:
RC has depression and anxiety following domestic abuse
and was living in Women’s’ Refuge. FTA 2x WCA and ESA
awarded. Appeal lodged then reversed on ESA. DWP
agreed to the mental health assessment.
PROPOSAL: more local medical centres, availability of PIP assessments at claimants home where appropriate. Remove automatic ‘2 strikes and you’re out’ for FTA’s, DM’s to assess all evidence/obtain evidence for ‘good cause’ for FTA.

4.2 Claimants with mental health problems can find it difficult to get information over at face-to-face appointments due to lack of insight, distractions caused by voices, delusions etc meaning the full extent of their problems are often not picked up on. Mental health carries a stigma and people feel ashamed or embarrassed to tell a stranger that they do not wash, cook, want to take their own life. This is especially the case where the person experiences symptoms of paranoia or where they fear their responses could lead to being sectioned to hospital under the Mental Health Act or their children taken into care. A snapshot from a short medical on one day is therefore not an effective way of assessing a person’s mental health, and for people with mental health problems their Care Co-ordinator (CPN or MH Social Worker) or Psychiatrist, who have worked with them over a period of time and have gained their trust, are often best placed to comment on their condition and its effects. Some PIP decisions could therefore be made from reports by involved mental health professionals thus avoiding the claimant having to attend a stressful assessment. A PIP decision could also be based on an indication of the severity of the claimant’s mental ill health such as the number and frequency of mental health professionals involved/ hospital admissions, level and type of medication, ongoing intensive input from Mental Health Services under a CPA (care programme approach), Section 117 Mental Health Act after care on coming out of hospital or Community Treatment Order all of which indicate a high level of need/support.

Example
JC has psychosis with delusions, on high dosage anti-psychotic medication, under Psychiatrist 3mthly, Community Mental Health Team regularly involved. JC thinks everyone is an alien including the HCP with no insight into condition, therefore only told HCP had back problems who then assessed JC as having no difficulties. Decision overturned at appeal as at risk of harming self or others due to delusions.

PROPOSAL: Specialist mental health workers based in DLA Units to oversee mental health claims eg by following up non-return of forms, obtaining relevant evidence from appropriate mental health professionals, assessing severity of mental health from all the relevant evidence.

4.3 At present ESA claimants are complaining of unempathetic assessments by HCP’s at the medical centres such as just looking at the computer screen with no eye contact, only allowing very short answers cutting people off before they have fully explained their difficulties, not allowing a support worker in/ say anything, recording inaccurate information, making assumptions (for example that they have got to the assessment on their own because they are on their own in the waiting room), not referring to the claimant’s completed form or supporting evidence.

Example:
AM has bipolar with severe depression. At time of assessment had 2 recent serious suicide attempts (to gas self in car), under Psychiatrist 3mthly, Mental Health Crises Team weekly and on anti-psychotic, anti-depressant and mood stabiliser medication at high doses. HCP changed report from ‘customer attempted suicide 6 mths ago, currently has firm detailed plans for self harm’ to ‘frequent thoughts of self harm but no specific plans’ with no explanation, and assessed as having no problems – over turned at appeal based on level of medication prescribed.

PROPOSAL: Specialist mental health HCP’s to assess mental health cases.
4.4 There seems to be limited knowledge of mental health issues by DM’s and HCP’s with no experience within our group (which covers all the NW) of the presence of the Mental Health Champions at the medical centres as proposed by Professor Harrington’s review of ESA procedures. Claimants with serious mental health problems (schizophrenia, bi-polar etc) or no insight into their ill health or who have difficulty communicating with strangers or who use alcohol/drugs to subdue symptoms of their underlying mental health condition, can all be incorrectly assessed as having no problems, often for the decision to be overturned at appeal. The President of the Appeals Tribunals annual report 2006/07 found that DM’s did not sufficiently pursue mental health issues, did not appreciate the impact of mental ill health on disability questions and did not try to resolve mental health issues before going to appeal; our group’s experiences find that these issues still do not seem to have been resolved. This poor quality of assessment and decision-making indicates a need for better training in mental health issues by DWP and Atos officers and is reflected in NWMHWRgp members’ appeal outcomes where mental health is the main issue:

- Rochdale Council Mental Health Worker: DLA 11 appeals, 10 overturned at appeal (91%)
  Jan – Aug 11; ESA 15 appeals, 14 overturned (93%) Jan – July 11
- Manchester Council Mental Health Advice Workers Team: ESA 18 appeals, 14 overturned (77%) Jan – June11
- Stockport Welfare Rights Worker: DLA 11 appeals, 3 successful, 7 superseded, 1 unsuccessful (91%); ESA 6 appeals 1 successful, 4 superseded, 1 unsuccessful (83%) Jan – July 2011

PROPOSAL: increased mental health training for DM’s and HCP’s, presence of MH Champion in all Medical Centres, random quality checking of HCP reports, feedback to DM’s and HCP’s of decisions overturned at appeal, penalties for incorrect Atos reports.

4.5 The current Lima IT programme to assess ESA, which it seems will be adapted for PIP assessments, is inappropriate for many mental health claimants. The mental health functional assessment has no relation to people’s actual mental health problems and are often ignored by the HCP eg referring to ‘ruminating, trembling, rocking movements, arousal, insight’.

PROPOSAL: appropriate functional assessment for mental health claimants, HCP’s to explain why function is / is not chosen (without use of automatic drop down box which reverts to ‘norm’).

4.6 Claimants are currently dropping out of the ESA system, not necessarily as the media report because they are fit for work, but, especially for claimants with mental health problems because they do not deal with correspondence; cannot attend the assessment; have no insight into their ill health; cannot communicate their difficulties; cannot face a further assessment following a negative experience of one; do not realise they can appeal; cannot face the appeal system; delays in the appeal system etc leading to loss of benefit entitlement.

PROPOSAL: research into why people drop out of the system and introduction of measures to address these reasons such as local medical centres, user-friendly assessments, shorter appeal turnover times.

**Summary:**
To ensure PIP addresses the major issues raised above the NWMHWRgp proposes:

- mobility components equally accessible to mental health claimants
- criteria to include social engagement
- allocate high score for managing treatment and medication
- criteria to include supervision needs
- criteria to include night time needs
- claim forms to include a diary format to address fluctuating conditions
- more local Medical Centres
- exemptions from attending assessments for claimants with severe mental illness
- specialist mental health worker in DLA Units
- specialist mental health HCP’s
- increased mental health training for DM’s and HCP’s
- presence of MH Champion in all Medical Centres
- feedback to HCP’s and DM’s of any decisions overturned at appeal
• published guidelines for HCP’s expected standards/conduct
• audio recording of assessments
• random quality checking of HCP’s reports
• Atos penalties for incorrect reports

August 2011
Written evidence submitted by Ecas (PIP 20)

Executive Summary

Ecas is a charity devoted to helping people with physical disabilities. This submission of evidence addresses four of the areas of concern that Ecas has over Disability Living Allowance (DLA) reform: the draft Personal Independence Payment (PIP) assessment, the contracting out of the assessment, possible overlap with local authority services, and the justifications for reform.

Section two, on the assessment, addresses concerns arising from the limited nature of the draft assessment criteria. We are concerned that: the new benefit will only support people to the point of basic survival; that the assessment criteria is too narrow; that it risks not covering additional costs incurred despite using an aid; that it reverts back towards the medical model of disability; and that it risks penalising people with complex or fluctuating conditions. These are concerns that have been raised by people with disabilities to whom we have spoken. They are backed up by examples from the draft assessment.

Section three draws on evidence from contracting out the Work Capacity Assessments and raises concerns about this process being used for PIP. Despite the assurance that lessons have been learned from the Harrington report, we believe that it would be worthwhile to put in place some safeguards, such as an independent regulatory body, the requirement to hire mental health specialists, and the ring fencing of funds to ensure legal aid and advice is provided for those wishing to appeal.

Section four provides examples from Ecas’ own experience of the possible overlap between DLA and local authority provision, and addresses specialist equipment and aids, care packages, and transport. In our experience, DLA acts as a vital contribution towards these areas for our clients, and works alongside local authority provision to contribute towards achieving equality of access. As Ecas helps to cover the cost of transport for some of our clients and runs a grant scheme that contributes towards the cost of some specialist equipment, we fully appreciate the necessity of local authority provision and the role of DLA in helping to provide more comprehensive support.

Section five addresses the case for reforming DLA. We believe that the case has not been clear and transparent, has used some questionable statistics and sound bites, and has omitted certain other pieces of information. This has left the justifications open to a high degree of misinterpretation about the state of DLA to the media and by the general public. In this section we provide examples of when this has happened and provide further evidence from Department for Work and Pensions statistics and House of Commons committee reports to highlight where this has been open to misinterpretation and to clarify the state of the benefit. As these concerns are very similar to what has happened with ESA statistics, which the Work and Pensions Committee rightly highlighted, we believe that it would be worthwhile to bring this to the attention of the committee.
Evidence to the Work and Pensions Committee from Ecas

1 Ecas is a charity devoted to helping people with physical disabilities in Edinburgh and the Lothians that runs activity classes, a grant scheme, and a befriending project. We have concerns over a number of aspects of Disability Living Allowance (DLA) reform, spanning the assessment, the contracting out of the assessment, perceived overlap with local authority services, and the case for reform put forward to the media. These concerns have come from meetings with our own clients, events with service users of other charities, our experience running programmes for our clients, and research conducted by Ecas into statutory provision of services and welfare reform.

2 **Assessment**

2.1 The draft assessment regulations appear to support the claimant only to the point of basic survival, rather than towards independence and fulfilling their potential. The indicators on preparing and cooking a “simple meal” risk leaving the claimant living off ready meals or beans on toast. The indicators on washing, bathing, and grooming are only to the low threshold of “above the level of self-neglect”. There are no provisions for allowing the claimant to participate in society, have social interactions with others, or take part in recreational activities. This forms a vital part of a person’s well-being and quality of life. The closest indicators appear to be the individual’s ability to plan a journey or go to the shops, which does not cover actually participating in a social activity outside of one’s home.

2.2 A number of service users have expressed concern at the limited nature of the draft assessment criteria. Ecas shares these concerns and feels that the criteria do not take into account the complex nature of many conditions, particularly for those with fluctuating conditions and/or multiple conditions. We believe that there should be space on the assessment for the applicant to describe their condition and how it affects them, and that there should be a procedure for gathering additional medical and non-medical evidence, such as that which exists in the current DLA application process. Furthermore, we believe that it would be beneficial for the application process to pay more regard to independent evidence, as it would provide a more objective analysis of the applicant’s condition from a professional who has experience with them.

2.3 The policy of reducing payments for those who have aids flies in the face of the general thrust of policy which is towards independence, self-fulfilment and encouraging individuals to help themselves. The assumption that being able to move with an aid means less financial support is required is flawed. For example, Ecas works with many clients who have severe mobility impairments and use an aid to help them move around. However, they still face many obstacles when moving outdoors, such as difficulty moving over certain types of terrain, broken or unmaintained pavements, lack of dropped kerbs. Even though accessibility to buses has improved, these obstacles still mean that many of our clients have to rely on taxis for transport, particularly those who live in rural areas without accessible transport. An arbitrary measure of the ability to move 50 or 200 metres does not take these factors into account.
2.4 The draft regulations for PIP revert back towards the medical model with an individual-centric focus. The indicators focus entirely on the applicant and ignore any social and external barriers that block their independence, such as: the availability and accessibility of transport and the obstacles to mobility highlighted above (paragraph 2.3). These external factors often account for many of the additional costs faced by a person with a disability, which is recognised in the social model of disability. This will also create a disparity between the Self-Directed Support policy in Scotland, which could adversely affect those who rely on the state for assistance. This also goes against the international consensus on approaches to disability, as outlined by the UN Convention on the Rights of Persons with Disabilities and by the World Health Organization, both of which pay regard to external factors.

2.5 It is not clear how fluctuating conditions and the use of aids will be treated under the toughened approach to benefit claimants. The Welfare Reform Bill will introduce a £50 (with the possibility of being raised to £300) penalty for not maintaining claims, with the Impact Assessment stating “it is a customer’s responsibility to make sure that the information held by the Department is correct and up to date at all times and what they tell us is truthful”. This will cause additional stress for those with a fluctuating condition, or someone taking steps to manage their condition better. This policy risks criminalising simple mistakes made by a group of society more prone to making them.

3 Contracting Assessments

3.1 The evidence from the contracting out of the Work Capacity Assessment has not been reassuring. The Work and Pension Committee’s report has highlighted the grievances felt by individuals over the way they have been treated and has noted that the standard of service has fallen below acceptable levels. Further research commissioned by the Department for Work and Pensions has mirrored these findings. Inevitably, many Ecas clients are concerned about similar problems affecting PIP, and have noted that remedying these problems took considerable time. We believe that if a private contractor is to carry out these assessments there should be safeguards put in place: (a) an independent regulatory body set up to review a selection of assessments and to act as an ombudsman, (b) the requirement to employ mental health specialists to conduct assessments for applicants with mental health conditions, (c) adequate funding set aside for advice and legal aid for claimants wishing to appeal.

4 Overlap with local authority provision and the implications of reduced expenditure

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4.1 DLA has the capacity to overlap with other services in three areas: specialist equipment, care packages, and transport. However, we do not believe overlap to be an accurate term to describe this. DLA helps to contribute towards and work alongside local authority provision in order to provide adequate state assistance. However, research shows that state assistance still fails to cover the full additional costs of having a disability⁴ and that DLA recipients do not feel the benefit meets all of their needs.⁵

4.2 Some individuals purchase specialist equipment or aids using their own income, which DLA contributes towards. Ecas conducted research to find out where our own grants scheme overlaps with local authority provision, which covered the provision of specialist equipment. We found that individuals have opted to purchase their own equipment due to: local authority waiting lists; wanting a specific item that the council has refused to fund (even when the item has been recommended by an Occupational Therapist); and due to strict eligibility criteria, particularly concerning NHS provision of power wheelchairs. Although local authorities and the NHS have the duty to provide specialist equipment and aids, we believe that many individuals end up using their own incomes to purchase these items.

4.3 DLA is often used by local authorities to contribute towards the cost of care packages. Due to current funding arrangements for social care, this can end up costing an individual a significant sum of their savings, as outlined in the Dilnot report.⁶ One Ecas member has a proportion of his DLA, along with his ILF, contribute towards his care package. Another person Ecas spoke to has a proportion of her son’s DLA Care go towards a carer, along with his Direct Payments. Someone in a similar situation trying to set up a care package in the future would lose out from the closure of the ILF, and potentially from reductions in spending on DLA/PIP. As DLA plays a vital role in providing care, particularly as local authority budgets tighten, any reduction could seriously reduce quality of care.

4.4 Transport can constitute a significant cost for Ecas clients, as many have severe mobility impairments. This cost is not always fully covered by DLA mobility. The additional cost is due to individuals with severe mobility impairments having to use taxis for many of their transport needs, as highlighted in paragraph 2.3. City of Edinburgh Council provides some services to help with this, such as Taxicard and Handicabs. However, these schemes are rather limited and often do not cover the full additional cost. Taxicard provides the user with a reduction in their taxi fare; however, it has not been uprated in line with inflation for many years and its funding is currently being reviewed, with the possibility of it being reduced. This is worse for over 65s on Attendance Allowance, as this benefit does not contain a mobility component.

5 The case for reform

⁵ Disability Benefits Consortium ‘Benefiting Disabled People? A report by the Disability Benefits Consortium looking at the support offered to disabled people and people with a health condition by the benefits system and how this support could be improved’. 2011 <http://www.disabilityalliance.org/dbcreport.htm> [accessed 15 Aug. 2011]
5.1 Ecas has concerns over the case for reform of DLA and the way in which it has been portrayed to the media. This is similar to some of the concerns raised by the Work and Pensions Committee7 and the UK Statistics Authority8 in relation to the way in which ESA claimants have been portrayed and the role of the DWP in disseminating these statistics. On a number of occasions information has originated from the DWP, and sometimes been reported directly to the media, that we do not believe to be representative of the benefit. This creates an inaccurate picture of the benefit that is further compounded by the omission of established statistics, such as the low fraud rate of DLA.9 If DLA is to be reformed properly and continue to help people with disabilities, then it needs to be based on clear, accurate, and transparent debate.

5.2 The impression has been given that DLA claimants are not reviewed and that there is no mechanism for review. It has been publicly stated that 130,000 DLA claimants have not been reviewed since 1992,10 that a quarter have not been reviewed in the last 10 years,11 and that there are no mechanisms for review.12-13 However, the source of these statistics, released several weeks after these comments, provides vital context that appears to have been omitted.14 It states that about 130,000 have not had their payment changed since 1992, which is also the maximum possible number of people who have not been reviewed. Upon further contact with the researcher, Ecas found that this 130,000 figure for those whose payments have not changed includes those reviewed by the Benefit Integrity Project, the Period Reviews, the Right Payment Programme, and by claimants contacting the department themselves.15 This also highlights three of the review mechanisms used by the DWP. In addition to this, the source also states that 77% of new applicants receive a fixed term awards, and so would have to renew their claim at some point.16 This process includes notifying the department of any changes to need and acts as a review mechanism. It is notable that the DWP press release in

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7 Work and Pensions Committee. The role of incapacity benefit reassessment in helping claimants into employment
13 Comments by Maria Miller, Minister for Disabled People during House of Commons debate. 11th January 2011.
15 le Roux, S. (8 April 2011) RE: Question on ad hoc DLA statistics. [email to R. Pye], [Online] (Robbie.pye@ecas-edinburgh.org)
16 Department for Work and Pensions ‘Analysis of Disability Living Allowance: DLA Awards’ (p. 12)
footnote 11 now states “not had a change to their award, or their award looked at” in relation to these statistics, which was edited after we queried them. It is, however, still misleading, and the DWP press release is only one of these misleading sources. Without the context outlined in this paragraph, the statements concerning the review of DLA claims could be misinterpreted to imply that the benefit is open to large amounts of abuse. It is also notable that the source of the DWP source of these statistics was not publicised; rather, it was published in the ad hoc research section of the website.

5.3 Statements made to the media by the DWP have claimed that half of DLA applicants do not have to provide additional evidence.17-18 However, this does not appear to provide the full picture. The statistics released by the DWP, again released after these public comments, show that in 2010 48% of new claims required additional medical evidence, 36% required further non-medical evidence, and only 16% required no additional evidence.19 The statements made to the media appear to have referred to medical evidence, and on one or two occasions they have specified this; however, this still portrays DLA as being open to significant abuse as it implies that half do not have to provide additional evidence. It should be noted that this claim was also the basis for a Daily Mail article titled “the great disability benefit free-for-all”, leading to complaints to the PCC.20

5.4 The caseload for DLA has been highlighted as being unsustainable and out of control, with the rise of 30% in 8 years cited as a problem in the consultation document.21-22 In the context of the statements concerning DLA highlighted above, this gives the impression that DLA is being defrauded, which is how newspapers such as the Telegraph have interpreted it.23 However, these comments do not appear to take into account a review of the benefit conducted in 1998. A report by the Social Security Select Committee estimated that only about 50% of those eligible were claiming DLA in that time, although take up rate varied considerably depending on component and age.24 As the caseload back in 1998 was about 2 million, this would indicate that about another 2 million were eligible but not claiming. Over the last 10 years the caseload has risen by over a million to 3.2 million, still short of the total estimate of those eligible. This indicates that the rise in caseload was by perfectly legitimate claimants, as intended by steps taken to

18 The Guardian. 'Live Q&A: The minister in charge of the Disability Living Allowance takes your questions'
address the take-up problem, rather than the caseload being “out of control”. When presenting figures on the growth in the caseload of DLA, care could be taken by the DWP to ensure that they are not misinterpreted by the media or the general public. This 1998 report also highlighted several flaws in the DLA system - including the lack of a review mechanism and the common use of indefinite awards – which were addressed over the following decade.

5.5 Concerns have also been raised about the conditions of those eligible for DLA. During the Hardest Hit protest on the 11th May, in which thousands of disabled people took to the street to protest, the Minister for Disabled People gave an interview to the BBC in which she stated that “it can’t be right that we have a benefits system where under DLA more people who are either alcoholics or drug addicts are in receipt of the higher rate of Disability Living Allowance than people who are blind”. However, the official statistics show that this is only the case for higher rate DLA Mobility; but not for DLA Care. Furthermore, a comparison for these two groups on mobility grounds is not straightforward as it is only since April 2011 that higher rate DLA mobility has been available on the basis of visual impairment. The DWP estimates that up to 23,000 are eligible but have not have started claiming yet. As the Minister’s comment was made to the BBC at a time guaranteeing increased attention to disability issues, its inaccuracies could have a greater effect on the debate over the reform of DLA.

August 2011

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26 Department for Work and Pensions ‘DLA caseload by level of care and mobility components and disabling condition’ 25 February 2011

Written evidence submitted by the MS Society (PIP 21)

About multiple sclerosis
Multiple sclerosis (MS) is one of the most common disabling neurological conditions affecting young adults. Around 100,000 people in the UK have MS. For most people, MS is characterised by relapses followed by periods of remission while for others it follows a progressive pattern. The causes of MS are unknown, there is no cure and the treatments that are available are effective in only certain cases and for some of the time. MS symptoms include loss of mobility, pain, fatigue, visual impairment, numbness, loss of balance, depression and cognitive problems. MS can lead to severe and permanent disability.

About the MS Society
The MS Society is the UK’s largest charity for people living with MS, with almost 38,000 members and over 290 local branches offering support and services around the UK. The MS Society is the UK’s biggest funder of research into MS. We provide grants, an award-winning Helpline and information for people affected by MS, invest in MS specialists and put MS on the agenda locally and nationally.

1. The need for DLA reform
1.1 While we recognise the Government’s arguments for the need to reform, given the increasing caseload and expenditure, the MS Society receives relatively few queries or concerns from individuals with MS about DLA. On the whole, anecdotal evidence suggests that the benefit is well understood and highly valued by people with MS. We have encountered relatively few problems with the current decision-making and review process, particularly in comparison with the level of concern and confusion around the assessment for Employment and Support Allowance (ESA).

1.2 The large majority of people with MS who receive DLA receive an indefinite award (94%).¹ This seems a sensible approach to those with an incurable, degenerative long-term condition (see our response below at section 4).

1.3 The Government has set an apparently arbitrary target of reducing the number of claimants by 20%, yet no evidence has been presented as to why this target has been set. Reducing the number of claimants by 20% by focusing on ‘those with the highest needs’ is likely to leave thousands of working age disabled people unable to meet the additional costs many face as a result of their disability.

2. The implications of a reduction in expenditure
2.1 We object to the approach to DLA reform as a manifest cost-cutting exercise, designed to save £1 billion.

¹ Hansard, 31 Mar 2011 : Column 427W, Written Answer to Margaret Curran
2.2 We are very concerned about the focus on those ‘with the highest needs’, and particularly what this may mean for people who currently receive the lower rates of DLA. It is important that the Government clarifies exactly what is meant by the ‘greatest need’. A recent report by Demos demonstrated that there is little clear correlation between high costs of disability and the functional impact of a person’s impairment or disability.2

2.3 The Disability Alliance estimate that over 750,000 disabled people will lose support as a result of this proposal. 69,000 people with MS currently claim DLA.3 11,600 of these currently receive lower rate care – we are concerned that the large proportion of these people may no longer be eligible for DLA under a new, higher eligibility threshold, leaving them unable to meet the additional costs many face as a result of their disability.

2.4 For many of these individuals, DLA is their only form of support: a large number of people with MS receive little or no social care support, as over eight out of ten local authorities now only supply care and support to those with ‘substantial’ or ‘critical’ needs.4 In these situations, DLA often performs an important preventative function, helping people to remain independent and preventing their needs from escalating, reducing the burden on care services. In recent surveys of people with MS who receive DLA,5 many people with MS highlighted this fact, with over a third of respondents telling us that they use their DLA to buy support or help from someone:

“DLA is often received by those who haven’t reached the point where they need paid carers coming into the home. It acts almost as a preventative measure. It gives enough for people to be able to pay someone for a little help from whatever source, which then means they can reserve their limited energy for other tasks such as working, being a mum or dad, a home-keeper etc.”

“Even if Fair Access to Care is amended to allow services to be provided on a preventative basis there is a fundamental difference between assessing eligibility for LA services and assessing for an entitlement to extra financial help because of a level of disability.”

2.5 The Dilnot Commission on adult social care also acknowledged that meeting lower level needs is essential to ensure prevention of higher or crisis level needs.6

3. The extent to which overlaps in funding exist

2 Wood and Grant; Counting the Cost, Demos 2010.
3 DWP statistics; Disability Living Allowance - Cases in payment (5% sample) Caseload (Thousands) : Main Disabling Condition; Feb 2011
4 ADASS Budget Survey 2011
5 Disability Benefits Consortium survey of 1449 people with MS who receive DLA in September 2010, and MS Society survey of 200 people with MS who receive DLA in September 2009.
6 Dilnot Commission, Fairer Care Funding, July 2011
3.1 We believe that taking the mobility component away from those in residential care would be a disappointing and regressive step. Evidence from provider organisations, local authorities and individuals, shows that the needs of people in residential care homes are not currently met by their local authorities or care homes.\(^7\) We hope that the ongoing Low Review will provide important evidence and clarification of the extent of such overlaps to help the Government to review this proposal.

4. Automatic entitlement

4.1 We understand why the Government wants to move away from a system where some health conditions or impairments mean an automatic entitlement to the benefit. Conditions and impairments can affect different people differently, and we therefore recognise and support the need to base claims on the needs and circumstances of individual applicants.

4.2 However, we believe that the fact of someone’s diagnosis with a long-term, degenerative neurological condition like MS should be taken into account to determine a) the type of assessment required to entitle them to the benefit, b) the length of awards and c) the frequency and method of any subsequent reassessments. We strongly recommend that individuals with long-term conditions like MS should be given longer-term or indefinite awards, and made exempt from face-to-face re-assessments.

4.3 Similarly, we believe that those diagnosed with a long-term degenerative condition like MS already receiving the highest levels of DLA, should be automatically migrated onto the highest rate of Personal Independence Payment (PIP) without any reassessment (see our comments on transitional arrangements, s.9.)

4.4 Given the manifest problems with assessing people with complex and fluctuating conditions like MS,\(^8\) we believe that people with a long term condition like MS should be entitled to the benefit on the basis of sufficient written evidence, without the need for a face-to-face assessment. We would instead encourage decision-makers to more routinely gather supporting evidence from a nominated healthcare professional in order to support such decision-making. Anecdotal evidence gathered by the MS Society indicates that this process currently works well, and it is far less onerous, stressful and costly than putting every applicant, regardless of their condition, through a face-to-face assessment. This was also a recommendation of the Harrington review of the Work Capability Assessment (WCA).

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\(^7\) Don't limit mobility: The impact of the removal of the mobility component of Disability Living Allowance from adults and children living in state-funded residential care, January 2011, co-produced by 27 leading disability charities.

\(^8\) For example, problems with the Work Capability Assessment for Employment and Support Allowance, particularly the difficulties of assessing those with fluctuating conditions like MS, have been well documented. See: Professor Malcolm Harrington, An Independent Review of the Work Capability Assessment, November 2010. Work Capability Assessment Review: Evidence from the MS Society, September 2010. Not working: CAB evidence on the ESA work capability assessment, Citizens Advice, March 2010.
4.5 MS is a degenerative long-term condition. Although the progression of the condition can vary widely from person to person, there is no cure and few treatments are available. Some people (around 15%) are diagnosed with a progressive form of the condition (‘primary progressive’), but most people start with the relapsing-remitting form. The majority (around 65%) then develop ‘secondary progressive’ MS, the second stage of the condition, after a number of years. Those with primary or secondary progressive forms of MS in particular will find that they have a more sustained build up of disability, and a more rapid increase in symptoms.

4.6 Once someone with MS has therefore been assessed as needing DLA (or PIP), their condition will never improve to a stage where they no longer need the benefit. Given the degenerative and often unpredictable pattern of MS for most people, individuals are also unlikely to be able to adapt significantly to their condition to reduce their need for the support that PIP can offer. We therefore feel strongly that longer-term or indefinite awards would be far more sensible and cost-effective, and that repeatedly reassessing claimants with long-term conditions like MS is unnecessary. Such assessments inevitably cause a great deal of undue stress to individuals. Stress has been shown to exacerbate MS, and in some cases even to bring on serious relapses. Putting DLA claimants with MS (and particularly the progressive form of the condition) through repeated and stressful reviews is therefore not only unnecessary expense for a system which is supposed to be designed to save the DWP money, it risks unintended and serious negative consequences for the health and wellbeing of the individuals at stake.

4.7 There are around 69,000 people with MS who receive one form of DLA or another. 65,000 of these people are currently in receipt of an indefinite award. Regularly reassessing 69,000 with a long-term degenerative condition would require significant expenditure by the DWP, for what would certainly mean no return on investment (as people’s needs, and therefore the amount of benefit they are entitled to, will not have reduced). Although the reviews could also identify that the claimant requires a higher level of DLA than they are currently receiving, we believe that a more appropriate way to identify these people is to allow individuals to report to the DWP a change in circumstances if their condition has deteriorated. We have not encountered any evidence that this system is not currently working for people with MS.

4.8 Should reviews be made compulsory for all DLA claimants, regardless of condition, we feel that reviews for people diagnosed with long-term degenerative conditions like MS should consist, at most, of:

a) a short phone-call or letter check-in to ask if there have been any material changes in condition; or

b) contact with a healthcare professional nominated by the DLA recipient to ask for evidence as to whether the individual’s condition has changed materially.
5. **Qualifying period**

5.1 We believe that increasing the qualifying period from three to six months will result in many more people finding themselves pushed into debt as they seek to manage the costs of their impairment, whether this be coping with adjusting to a sudden onset of their condition, or bearing the costs of increasing disability with a condition like MS.

5.2 The Minister for Disability stated that this is about distinguishing between long-term and short-term disabilities, so increasing the qualifying period should not impact on those with fluctuating conditions. However, the test asks whether the individual has had a ‘qualifying impairment’ for the previous six months – thus someone who has been diagnosed with MS for a long time, but has recently experienced an exacerbation of symptoms that would qualify them for the benefit, would have to wait for six months before they can receive the benefit. Similarly, someone whose condition fluctuates may find it hard to show that, as respects every time in the previous 6 months, ‘it is likely that if the relevant ability had been assessed at that time that ability would have been determined to be limited or (as the case may be) severely limited by the person’s physical or mental condition’.

5.3 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 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.

6. **PIP as a gateway to other services**

6.1 We believe that eligibility for Carer’s Allowance should link to both rates of the PIP daily living component, and that passporting to the Motability Scheme should continue.

7. **The assessment**

7.1 The Minister has stated several times that the Government is committed to PIP supporting participation and enabling disabled people to lead independent lives, and that the new benefit will be about promoting independence and social inclusion. However, we are concerned that the draft assessment criteria published by the DWP so far focuses only on those activities required for the bare essentials of existing and will fail to help disabled people to overcome the barriers many face to living independently and participating fully in society.

7.2 Although the first component has been renamed from ‘care’ component to ‘daily living’ component, it continues to focus on care and support needs, rather than focusing on the additional costs encountered by disabled.

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9 Hansard, 18 July 2011 : Column 595; Oral Question by Catherine McKinnell (Newcastle upon Tyne North)
10 Welfare Reform Bill, Part 4, s. 79(2)(a)
7.3 Many descriptors appear to only allocate points to someone where they need ‘continual assistance’ or ‘continual prompting’. This fails to take into account the impact of fluctuating conditions like MS, where someone may be able to wash and dress and manage toilet needs unaided on some days and may require a very high level of support on others.

7.4 We believe that, in order to fairly and accurately assess the impact of a fluctuating condition, the applicant needs to be asked about the frequency, severity and duration of their condition. It may be that such a measure is tagged onto the assessment as a separate descriptor or it could be integrated into the descriptors themselves.

7.5 Moreover, someone who can’t undertake an activity for, say, 3 months per year is still living with significant disability. We would like to know what the Government’s evidential justification is for choosing 6 months, and would recommend that consideration should be given to awarding some lower level of points to people with a long term condition who experiences significant difficulties for some of the time.

7.6 We recognise the Government’s desire to take better account of aids and adaptations, and welcome also that the assessment will only take into account those aids that are normally used by an individual, rather than any that might potentially help them. However, it is important that those who have significant reliance on aids and adaptations, such as a wheelchair, still obtain enough points to qualify for some level of PIP, in recognition of the limitations and extra costs that such reliance may entail. We are particularly concerned that the barriers created by reliance on mobility aids, such as a wheelchair, are not adequately recognised in the current draft of the assessment for the mobility component.

7.7 Our concerns on specific descriptors are covered more fully in the Disability Benefits Consortium (DBC) submission to the DWP on the draft assessment criteria, attached at Annex 1. I also attach draft alternative criteria put together by members of the DBC (at Annex 2), which we feel would cover a broader range of factors, and would more accurately address disability costs.

8. Communicating the changes
8.1 There is a high degree of anxiety, concern and confusion amongst people with MS about the prospective changes to DLA and introduction of PIP, which have been exacerbated by inaccurate and scare-mongering media reports which portray recipients of disability benefits as ‘scroungers’, and depict the Government’s welfare reforms as a means of ‘weeding out’
those who are ‘faking it’. This issue was importantly highlighted by the Work and Pensions Committee on their recent report on Employment and Support Allowance.

8.2 We believe that in order to assuage these fears, it is important that the DWP takes the opportunity as soon as possible to inform DLA recipients of the planned changes, how and when these will impact on claimants, when they can expect to hear more, and how they can feed in their views, opinions and experiences to shape the future of DLA/PIP. This could be done in a cost-effective manner by ensuring that this information is included at every opportunity in ongoing DWP or JobCentre Plus communications with claimants.

8.3 It is disappointing that the DWP did not take the opportunity to contact DLA claimants directly during the initial consultation process to incite them to share their views. In addition, the nine weeks allowed for the initial consultation was three weeks short of the recommended 12 weeks outlined in Government guidance.11 Compounded with the fact that this was spread over a holiday period, this significantly reduced individuals’ and representative organisations’ availability to add their views to the consultation.

8.4 The DWP should learn lessons from the process of moving Incapacity Benefit claimants over to ESA: a large amount of work has been done (and is ongoing) to develop and pilot a customer journey and communications which are effective. Many of these learnings could be applied to the transition from DLA to PIP.

9. Transitional arrangements
9.1 As stated earlier, we believe that those diagnosed with a long-term degenerative condition like MS already receiving the highest level of DLA should be automatically migrated onto the highest rate of PIP without any reassessment.

9.2 Plans to bring in the new benefit and re-assess all current claimants are estimated to cost £675m.12 Over 29,000 people with MS currently receive the higher rates of both care and mobility components of DLA.13 Given that there is a significant group of claimants like this, who require a significant level of support, and whose conditions will not have improved since they were awarded the benefit, automatic migration for these claimants would save a considerable amount of Government money.

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11 Code of Practice on Consultation, BERR, 2008
12 Disability Living Allowance Reform Impact Assessment, DWP, February 2011
13 DWP statistics: Disability Living Allowance - Cases in payment (5% sample) Caseload (Thousands) : Main Disabling Condition; Feb 2011
Written evidence submitted by Margery M Browning (PIP 22)

1. Brief Introduction
1.1 My submission is based on the experience of being physically disabled since teenage years and forty years of working with children and young people with disabilities and their families in the capacity of educational psychologist, university lecturer in special educational needs, researcher, HM Inspector of Schools and currently a member of the boards of two charities one providing for children and adults who are blind or visually and multiply impaired and the other children with social, emotional and behavioural difficulties.

1.2 In considering the issues raised by the Committee, I have restricted my response to those which relate to my direct experience.

2. Points in relation to the proposal to replace the DLA with Personal Independence Payments (PIPs)

Bullet points 1 and 2: The need for DLA reform
2.1 I applaud the Committee’s intention to review the need for DLA and believe that salient issues have been identified. I find it extraordinary that these issues have not been fully investigated prior to the Welfare Reform Bill being introduced to Parliament far less it being through the second reading in the Lords.

2.2 My personal and professional experience has convinced me of the tremendous value of the DLA (and the mobility scheme which preceded it) in supporting the independence and inclusion in society of children and adults with disabilities. Not only has it had positive impact on making lives easier and supporting access to personal independence and community engagement but it has played its part in preventing the mental and physical difficulties which result from exclusion. The great value of the DLA has been the kick start it has given to access to education, further and higher education and work with the result that individuals become net contributors to society. My experience of the use of DLA has been that this provision has not been misused by those with whom I have worked. On the contrary, I have often found myself encouraging people to make justified applications for DLA. The lives of some families would have been intolerable had they not had access to Motability to enable them to acquire transport to get their disabled children to the innumerable hospital appointments as well as a safe way of ensuring that the siblings of the disabled child get to school.

2.3 While the DLA has had the enormous benefit of not being taxable, there are strong arguments in light of the debt crisis for it now to be taxed. My personal experience was that the mobility allowance was crucial in helping me to access employment and further training and earn, but I would have regarded it as more than fair to pay tax as my earnings rose.

2.4 As it stands the DLA focuses on mitigating the barriers that children and adults with disabilities face in participating in all aspects of life, work and independent living and contributing to communities and society at large. The DLA promotes inclusion and enables people with disabilities whether children and adults, including people
past retirement age, to make their full contribution to society. While it supports employment, it is about so much more in terms of access to life and living.

2.5 The great advantage of the DLA is that it was based on the philosophy of trying ‘to level the playing field’ for people with disabilities to access independence and full participation in society. Such an approach is fully compatible with the United Nations’ Convention on the Rights of Disabled People which the UK Government ratified in July 2009. The Convention stresses, in Article 19, the importance of disabled people living independently and being included in the community with choices equal to others and, in Article 30, the importance of participation in cultural life, recreation and sport.

2.6 In contrast the philosophy underpinning the concept of PIP is confused and confusing. On one hand the Government’s stated intention is that ‘the purpose of the proposed benefit will remain the same to contribute to the extra cost of overcoming the barriers faced by disabled people to lead full and active lives’. However, the whole thrust of the proposed legislation and the DWP’s ‘Personal Independence Payment: initial draft of assessment criteria’ are based on the concept of ‘those with the greatest needs’. It is not made clear what the term ‘greatest needs’ means. Does this mean greatest needs in terms of the impact of disabilities or in terms of financial income? While there are tried and tested ways of determining the financial aspect, there are considerable, if not impossible challenges, in determining greatest need in terms of impact of disabilities. My experience in working with children and young people with disabilities has demonstrated that a person with a range of what may be termed minor disabilities may in fact be as handicapped as a person with a single severe disability. I think it is a retrograde step that PIP is directly related to employment and applies only to people of ‘working age’ and thus excludes children and people over the age of 65 many of whom may be continuing to work and many are contributing to their communities.

**Bullet point 6: The extent to which the PIP will act as a gateway to other benefits**

2.7 If PIPs are to be the gateway particularly to the Disabled Parking Scheme and Motability then this will exclude children and their families and people over retirement age. Also, as seems likely, if people currently receiving the mobility element of DLA are deemed not to measure up to the level of disability required to receive PIP they will not be able to go through the gateway although they may require the support afforded by being able to park close to essential services or to the support required to acquire motor vehicles and electric scooters or motorised wheelchairs.

**Bullet point 7: The design of the PIP assessment**

2.8 I have serious concerns over the design of the PIP assessment and was able to find out more about it at a consultation meeting run by the DWP. Among my concerns are the following.

- The exclusion of any assessment criteria relating to assessment of a person’s capacity to play a part in the life of their community flouts Articles 19 and 30 of the UN Convention on the Rights of Disabled People.
• No actual pointage system is laid out to ascertain levels of qualification for either the lower or higher levels of allowance. This leads to the suspicion that benchmarks will be created based on numbers of people and views of funding available.

• It is not clear if the overall score for a person’s ability to qualify will be derived from a summation of points on all 11 categories of assessment. If all are to be included many people will be immediately excluded although they may have significant difficulties such as getting around.

• There will be a tremendous waste of resources if every applicant has to be assessed on each of the 11 categories, whether these are relevant to a person’s situation or not. A DWP representative at the meeting indicated that this would be the case.

• The assessment criteria do not recognise that people will function at different levels depending on state of health at a particular time, level of effort demanded in certain situations and environments and even time of day.

• There appears to be no method of in-built quality assurance in relation to PIP assessments and decision making.

**Bullet point 8: The delivery of the PIP assessments**

2.9 There is a lack of clarity about the delivery of the PIP assessments, although the piloting over the summer may mean that clearer recommendations are available to the Committee. In particular it is not clear the extent to which claimants will be involved in self-assessment or carers playing a part in contributing to the assessment. Good assessment of people with complex disabilities requires to be undertaken over time. The proposal to train assessors who will meet with the claimant and assess at one meeting is likely to disadvantage people with multiple low level disabilities. There seems to be little attempt to draw on the knowledge and expertise of professionals and carers who know the individual with disabilities.

**Bullet point 9: How DLA/PIP should apply to children and people over the state pension age.**

2.10 As it stands clause 87 of the Welfare Reform Bill repeals the DLA in total. This immediately leaves children and those over the state pension age vulnerable. The two DWP PIP Policy Briefing notes resulting from the consultation on the Welfare Reform Bill, one entitled ‘Children’ and the other ‘People over 65’ recognise the needs of both groups but do not provide concrete indications of how entitlement to the equivalent of DLA will be safeguarded. The arguments put forward for the differences in relation to these groups are not strong. The argument that children’s needs are likely to change more quickly has some merit, but fails to recognise that the needs of some adults, especially those becoming disabled as a result of illness or trauma are also likely to change. Responsiveness to changes in individual circumstances should be part of a scheme covering all age ranges. The proposal that the DWP will take forward an approach to meeting children’s needs through the Department of Education’s Green Paper ‘Support and aspiration: A new approach to special educational needs and disability’, published in March 2011, is not relevant in Scotland where there are different approaches. No alternative is suggested.
terms of people over 65 there is an intention to ‘consult in due course’ and a proposal to use regulation-making powers but not time frame. Nowhere is there a clear commitment to continue the DLA for either children or those over 65 after the commencement of the Welfare Reform Act if it is passed in its current form.

3. Executive Summary and Recommendations for action

Executive summary
3.1 The Committee’s decision to undertake this crucially important review is very welcome. The DLA with its philosophy of giving children and adults with disabilities support to access all aspect of life including independence and choice needs to be fully recognised. There appears to be little recognition of the part played by DLA in enabling people with disabilities to contribute to the national economy and common good. The proposed PIPs appears to be based on supporting only those with the ‘greatest needs’, a concept which lacks clarity and, excluding as it does children and adults over the age of 65, appears only to be related to employment. The Welfare Reform Bill nearing its final stages repeals the DLA but put nothing concrete in place to safeguard these two excluded groups. The DWP’s PIP Policy briefing notes are not reassuring being based on vague intentions to take action without any time frame. Concrete arrangements need to be put in place to protect support for children and those over 65. One way of recouping some costs from severely disabled people who are not ‘most needy’ in terms of finance would be to tax PIPs in the same way that the state retirement pension is taxed. The criteria for assessing applicants for PIPs do not include consideration of the individual’s needs in relation to their inclusion in their communities and in culture, leisure and sport, surprising as these commitments are in the UN Convention of the Rights of Disabled People ratified by the UK Government. The proposal to assess every disabled person on all eleven assessment criteria whether relevant or not appears unnecessary and leads to the suspicion that many will be excluded because they do not score on each. The absence of detail on the scoring criteria is deeply concerning, indicating that cut off scores will be based on funding that is deemed to be available. It is very important that the role of the DLA as a gateway to other measures such as the Disabled Parking Scheme and Motability is recognised and arrangements are made to safeguard access to the services vital to the lives and welfare of so many disabled children and adults.

Recommendations for action
3.2 The Committee should do all it can to

- make the intention of that part of the Welfare Reform legislation relating to the DLA open and transparent, particularly in clarifying what is meant by ‘those with the greatest needs’;
- ensure that the proposals for repealing the DLA and replacing it in part with PIP are fully in line with the UN Convention on the Rights of Disabled People;
- to ensure that the needs of children and their families and people over 65 are protected when the DLA is repealed;
- improve the assessment criteria for PIP to include the inclusion of people with disabilities in the life of their communities;
• find solutions to protect access to Motability and the Disabled Parking Scheme for those with disabilities but are excluded from PIP as not having ‘the greatest needs’; and
• ensure that rigorous quality assurance arrangements are integral to implementing PIP.
Effectiveness of current decision and review process for DLA.

We have detected an increasing number of rejections of applications by decision makers. These include cases for renewal where our clients have been on DLA for some years. Many in that position receive zero points, awarded after very brief consideration. (Cases A B C D E)

We have noticed a tendency by decision makers to overlook the criteria for award of points. In particular the requirement to take “severe discomfort into consideration is frequently ignored. (Cases C & D)

There are also failures to consult GPs or other medical advisers. (Case A)

Despite official denials we are concerned that a culture has evolved whereby decision makers feel under pressure to reject claims without adequate consideration, often within a very short time.

Design of PIP Assessment

The plan to cut out the third rate for “daily living” (Care) reduces the scope for fair allocation of benefit according to actual effect of disability on applicant.

The activity-based criteria so far issued by the DWP are hard to assess as no points are allotted to the examples. However the combinations of circumstances envisaged are complex and appear pretty arbitrary. It is arguable that the present system, of specified activities for which assistance is needed, is easier to follow and less likely to leave out applicants who have genuine problems.

The section “Communication with others” omits reference to the handling of business/official correspondence.

As regards ”moving around”, the omission of any reference to pain and discomfort is serious. (See cases C and D which would lose an important criterion under the new system – even though the current rules are not being applied.) The omission of such activities as getting in and out of bed and moving around indoors is likely to penalise many applicants.

Delivery of the assessment

The plan is to outsource assessment under contract, presumably requiring the majority of applicants to attend a medical.

There must be serious concern that the procedure would follow the pattern used for the Work Capability Assessment of the ESA, which has a number of flaws, even following the review by Professor Harrington. In particular we urge that the brief should stipulate the need for objective assessment based on evidence that includes applicants’ own medical advisers’ reports. There should be no reward for contractors simply meeting targets for benefit reduction.

Overall effect
We believe that the basis of the current DLA, intended to provide disabled people with the means to lead something nearer to a normal life, is a sound one. However the evidence shows that the rules are not always properly applied. This is already leaving a number of people without adequate provision. We are concerned that the tendency to reject applications will carry over into the new system and also that the proposed changes will leave a number of gaps in the application process so that genuine disabilities will be overlooked. The fact that the proposals are accompanied by a substantial planned cut in funding suggests that saving is a key motive for the changes.

August 2011
About Papworth Trust

1. Papworth Trust is a disability charity and registered social landlord, whose aim is for disabled people to have equality, choice and independence. Papworth Trust helps over 20,000 people every year through a wide range of services including employment, vocational rehabilitation, housing and personal support.

2. Papworth Trust welcomes the opportunity to submit evidence to the Select Committee Inquiry into the migration from Disability Living Allowance (DLA) to Personal Independence Payment (PIP). In anticipation of the inquiry, Papworth Trust ran a survey on the changes to Disability Living Allowance (DLA) throughout August 2011 and received 2,286, 80% of whom (1,829) currently claim DLA. The purpose of the survey was to find out what claimants currently use their DLA for, to test public opinion around the introduction of assessments and re-assessments under PIP, and to better understand what changes (if any) were causing disabled people most anxiety and concern. We have used our survey results to inform this response.

DLA reform and implications of a reduction in expenditure

3. Papworth Trust is supportive of DLA reform in principle. We favour a simplified system that better reflects the additional costs that disabled people face if they wish to continue to live with the degree of independence which they have chosen. Papworth Trust believes it is important the design of the new PIP to reflects how current claimants of DLA spend their benefit. Our survey found that disabled people tend to spend their DLA on areas such as specialist transport, household goods (including food, drink and basic housekeeping) and utility bills.

“Basically it [DLA] allows me to have a level of dignity and not be scraping around on nothing.”

4. The Government has made clear its ambition to reduce the total amount it spends on this benefit by 20% through these changes, although it has not yet stipulated whether this will be a reduction in the rates of payment, claimant count or a combination of both. Our survey showed that four in five people thought the Government’s target of cutting total spend by 20% was too arbitrary – feeling it implied that either costs associated with having a disability had fallen by 20% or that 20% of claims were fraudulent. By contrast, we found only 5% of respondents felt that having their benefit reduced or stopped altogether under PIP would have no effect. This supports the Government’s
view that not everyone who currently receives DLA needs it to maintain their standard of living, but rejects the view that 20% is a fair target.

5. Many of the concerns put forward by respondents for maintaining the current system centred on the feeling that the Government was creating its own catch-22 situation – reducing or cutting entitlement would make their health or condition worse, meaning they would require additional, more costly, support from the state in the longer term.

6. Under our survey, 74% said they would not have enough money for everything they need and 63% said they would be less independent if their benefit was reduced or stopped under PIP. In terms of their spending, the three areas they said they would reduce or cut spending on were household goods like food and drink, utility bills and specialist transport. This is perhaps unsurprising given that for current claimants these are the also the highest three spending areas.

**Automatic entitlements**

7. Papworth Trust would like clarification on which claimant groups will be granted indefinite awards. Respondents to our survey felt that periodic re-testing was a waste of resources for those claimants with a long-term disability where it was clear their condition could not improve, particularly for those born with that condition. The Government has indicated that in exceptional circumstances claimants will be granted on-going awards under PIP, but it is not clear what the criteria will look like nor what proportion of claimants are likely to qualify indefinitely.

“My opinion is divided. Re-testing is a good thing for some people, who condition worsens or develops over time (like my own disability), or for people who may get better over time. For others, who have a chronic, un-changing disability, it would not only be a waste of time, it would cause people stress and worry needlessly”.

**Assessments and re-assessments**

8. Papworth Trust’s survey shows the public is split on the issue of assessments and re-assessments. The greatest concern for people about the changes is the fear that the assessment for PIP will be unfair.

9. Disabled people told us they would like to have their say in what period of reassessment was right for them. The Government has rightly recognised that conditions can change over time – for some this will mean their condition will deteriorate and for others they will mean their condition will improve. Whilst
longer periods of reassessment, for example every five to ten years, were preferred by many due to the stressful nature of reassessment, others expressed a desire to ensure their assessment periods were shorter as their condition changed more rapidly. Whilst we understand the independent assessor will make a recommendation on how frequently a person should be assessed, Papworth Trust believes there needs to be a role for the claimant and their doctor or healthcare professional to make similar recommendations.

10. The chief concern of respondents expressed that reassessment would automatically lead to a downgrading of the benefit. Further concerns were expressed about the role of assessors and whether they would be able to identify conditions, particularly hidden disabilities, mental ill-health and fluctuating conditions. Respondents felt that only a claimant’s own doctor, consultant or other healthcare professional could properly understand the effect that their condition has on their daily life, and it is therefore imperative that information from these sources is given adequate weighting at the decision-making level. Papworth Trust feels concerns of this nature have been amplified by changes in the Work Capability Assessment to address evident shortcomings in this area.

Passporting arrangements

11. Through our survey, Papworth Trust found that the most commonly claimed benefits for DLA claimants were the Blue Badge, free bus pass, Council Tax Benefit, Housing Benefit, and Incapacity Benefit. Respondents said it was important that benefits like the Blue Badge were not solely accessible via DLA and should not be so under PIP. We received many responses to say that whilst people were ineligible or yet to receive DLA, their Local Authority was able to grant them a Blue Badge. It was an important part of enabling them to maintain their independence, even without DLA.

“It took me years to get DLA, I was constantly turned down. But having my Blue Badge allowed me to work and go out. If they link PIP and [the] Blue Badge together, I would have lost all of that”.

Aids and adaptations

12. Papworth Trust welcomes a commitment to continue to award points to individuals who can complete activities only with the assistance of an aid or appliance and that the assessment will only take into account aids or appliances that are normally used by an individual, rather than any that might help them in the future. However, without knowing how the points will be allocated it is difficult to understand if, and how, aids and adaptations will penalise claimants on some descriptors.
13. As the Government is aware, DLA currently acts as a passport for funding for many aids and adaptations, for example social budgets and wheelchair services. We are concerned the situation may arise where claimants receive a lesser PIP award because they are using aids and adaptations, and consequently do not qualify for future funding for this equipment because they do not have the right level of PIP. We ask that this is taken into account and considerations are put in place when developing the new passporting arrangements for PIP.

**Funding overlaps and mobility payments to those living in residential care**

14. Papworth Trust believes that DLA provided to people in residential care can empower their choice and independence, resulting in greater equality. Research by Mencap\(^1\) does not support the suggestion that mobility support is double-funded. Papworth Trust is concerned that removal of this component from this group of disabled people will stifle the independence of 80,000 people.

“My son is autistic and lives in residential care. One day a week he attends a day centre in Ipswich; using a mixture of taxi’s and public transport, he spends £8.80 each way to get to the centre. In addition to his activities at the centre, he has a voluntary job. By withdrawing the mobility component of Disability Living Allowance to people living in residential care, he will have to live on £22.36 a week”.

15. Papworth Trust believes that the additional expenses incurred by disabled people (for example, the increased cost of an accessible taxi) are equally applicable to those living in residential homes. Just like disabled people who do not live in residential homes, the mobility component of DLA is also necessary to meet other day-to-day expenses. Papworth Trust supports the retention of the mobility component of DLA and PIP for disabled people in residential care.

**The pilot trials**

16. Papworth Trust welcomed the Government’s intention to pilot the new assessment and review the results early on in the process, with opportunities for further revision prior to the regulations being laid in Parliament and the assessment being fully rolled out. However, we were disappointed that

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\(^1\) Mencap et al, Don’t limit mobility, January 2010
volunteers had already been recruited before the publication of the policy papers. Papworth Trust, along with other organisations who have been involved in the consultation groups, would have liked the opportunity to propose volunteers to take part in the pilot. We feel this is a necessary and important part of many organisations’ involvement in the process and would have helped to increase understanding and confidence of how effectively the assessment operates.

17. We are concerned by the decision to recruit volunteers largely from the existing DLA caseload or have had a claim for DLA refused in the past. We feel that this may lead to an under-representation of people with mental ill-health within the pilot study, an issue that has caused problems with other medical assessments including the Work Capability Assessment. Anecdotal evidence from mental health charities\(^2\) suggests that there are a huge number of people not claiming DLA who are eligible. We therefore urge the Government to rectify this in their pilot to ensure that a wider variety of situations and conditions are considered.

**Points allocation**

18. Papworth Trust’s comments on the draft assessment are extremely limited given the allocation of points to the proposed criteria have not yet been published. Furthermore, the handbook for assessors, which will explain how they should interpret these descriptors, has not yet been drafted. It is therefore difficult to fully understand the consequences of these descriptors and whether our comments have already been considered by the Department and mitigations put in place.

**Designing the new PIP assessment**

19. As mentioned under paragraph 3, our survey found that disabled people tended to spend their DLA on areas such as specialist transport, household goods including food, drink and basic housekeeping and utility bills. Whilst the draft assessment criteria under PIP cover mobility and food drink, they take no account of the additional utility costs faced by disabled people. Previous research carried out by Papworth Trust\(^3\) has shown that severely disabled people find themselves at home for longer periods of the day, and are therefore faced with higher energy bills as a result of heating their home. We have also gathered some anecdotal evidence that some disabled people, as a

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\(^2\) Disability Living Allowance reform consultation, DWP – 6 December 2010. Joint response from Centre for Mental Health, Hafal, Mind, Rethink, the Royal College of Psychiatrists and the Scottish Association for Mental Health

result of their condition, may take longer to shower, wash or bathe, which further increases utility bills.

“My utility bills are considerably higher than those of able-bodied people e.g. it takes an hour to shower me”.

Papworth Trust urges the Government to take this opportunity to:

- revise the draft assessment criteria under PIP and add a new descriptor which reflects additional utility costs faced by disabled people; and/or
- provide a passport from PIP to the Winter Fuel Payment to ensure severely disabled people are helped with the additional utility costs they may face.

**Daily Living Activities - Food and drink**

20. Papworth Trust’s survey found that half of current claimants spend their DLA on household goods, such as food and drink. We were pleased to note the draft assessment criteria makes important steps to take account of the additional costs faced by disabled people in planning, buying and preparing food and drink. However we are concerned that descriptor 1 places little emphasis on the importance of planning and buying food and drink that are appropriate and good for the claimant’s health. Some people may be entirely capable of planning and buying their own food and drink, but they may require additional guidance to make nutritionally sound choices. The descriptor in its current form does not take this into account and we would like to see this emphasised.

21. The descriptor also takes no account of the additional costs associated with ‘healthy food’. Our survey found that many claimants used their DLA to buy prepared fruit and vegetables as they were unable to prepare these foods themselves. Purchasing such ready-made items are often more expensive than unprepared ones.

“Food and drink = things like ready meals for when I can’t cook, the extra cost of pre-prepared vegetables”.

22. The decision to exclude physical ability to purchase food from the descriptor does not take into account the additional costs a person may face, such as the travel cost of using accessible taxis to and from the supermarket or the expense of having food delivered to their home. These factors are not dealt
with under the mobility component of the assessment and Papworth Trust urges the Government to review this immediately.

**Mobility Activities**

23. Transport is a key issue for disabled people with over half of current claimants spending their DLA on specialist transport to enable them to get around. Our survey also showed that if a person had their entitlement reduced or stopped under PIP, they would in turn cut their spending on specialist transport. Papworth Trust is concerned that the descriptors under Mobility Activities do not currently take into account the additional costs accrued from specialist transport – for example, purchasing mobility cars or taking accessible taxis. In addition to testing an individual’s ability to mobilise, we believe an additional descriptor is needed to take into account social factors such as the lack of an accessible public transport network in the local area.

“I’m a wheelchair user and can’t travel on buses as I have limited strength to support myself etc so therefore always require either accessible taxis or adapted vehicle”.

**Interaction with the Work Capability Assessment**

24. Papworth Trust has raised concerns about how the PIP assessment could be treated alongside the Work Capability Assessment (WCA). Whilst the contractor for carrying out the medical assessments has not yet been appointed, we can envisage a situation where a claimant is called for their WCA and PIP assessments on the same day, at the same assessment centre with the same assessor. These assessments test completely separate issues and claimants may therefore answer questions in very different ways. We believe careful consideration needs to be given as to how these assessments can be carried out effectively within a short time of each other, or what steps the Government will take to ensure they are kept entirely separate.

25. In addition, Papworth trust is concerned about the speed of the migration. Currently, the WCA migration is falling far short of its target to migrate 11,000 claimants per week. However, there are currently 2 million working-age claimants of DLA, and only 3 years have been mooted for migration. This implies a migration of 12,800 claimants per week. Given the experience of the WCA we question whether this is a realistic target. An extended migration period has the additional advantage of providing more time to communicate the changes to disabled people.

26. With regard to contractors, Papworth Trust is concerned that, whichever contractor is chosen, there will be insufficient consequences for the contractor
if assessments are delivered late or not at all, or if excessive numbers of assessment results are successfully overturned, for example at appeal. Papworth Trust recommends the contract include penalties for late or cancelled assessments, and for results which are overturned in recognition of the fact that these assessments and appeals are likely to be very stressful for disabled people.

**Learning from the WCA Assessments**

27. Papworth Trust believes that lessons can be learned from recent reviews, including the Harrington review, on the WCA. Disabled people’s experience of WCA has shown that better upfront support is needed for claimants when filling their forms and especially when they are called for assessment. In the past, notifications for assessment were sent out without warning and no further support is offered to help individuals to prepare for the process. In the design of PIP, consideration must be given to better signpost claimants towards a person or an organisation who can help them understand the benefit itself and the assessment process. It is imperative that information is provided in accessible formats, such as Easy-Read, and is made widely available.

August 2011
Written evidence submitted by Motor Neurone Disease Association (PIP 25)

Executive Summary

i. We do not accept the Government’s arguments for reforming DLA. It is a well-understood benefit and is in no sense ‘out of control’.

ii. We do not perceive any current overlaps in funding between NHS, social care and benefit provision.

iii. There appears to be a significant mismatch between the Government’s stated policy intention in respect of PIP and the draft criteria published by DWP. While PIP is intended to focus on supporting the individual both to live independently and to engage in wider activities in the community, the draft criteria examine only the basic essentials of living: washing, dressing, moving around and so on – things that social care is meant to cover.

iv. Although MND is a terminal illness, and the Special Rules system nominally exists for those who are terminally ill, it does not work reliably for people with MND. The definition of ‘terminally ill’ as meaning a prognosis of six months or less is particularly awkward for people with MND: half of people with MND die within 14 months of diagnosis, so while relatively few survive for fewer than six months after diagnosis, many more die shortly after this period.

v. We are deeply concerned that the present draft criteria will, if implemented without substantial revision, badly let down people with MND.

vi. Whether people with MND are granted the benefit will depend on the largely haphazard question of their exact condition at the time of their assessment. People with MND could therefore be incentivised to wait until well into their illness before claiming PIP.

vii. One of our key recommendations to the Government when they consulted on PIP was that assessment should be anticipatory: that is, it should take into account the future progress of MND, not just its progress to date at the time of the assessment. The current draft regulations appear to rule this out.

viii. We also recommend that claimants should be able to trigger an urgent review, so that a deterioration in their condition can be quickly taken into account.
ix. Once a person with MND is receiving the highest rates of PIP, there is no point reassessing them: MND is degenerative and there is no medical possibility that their condition will improve.

x. We do not support the proposal to take aids and adaptations into account: it would introduce such massive potential for error into the assessments that it would inevitably lead to many unjust decisions, and many more appeals.

xi. The relative weighting given to the face-to-face assessment and other evidence will be crucial. Where complex neurological conditions such as MND are concerned, expert testimony from health and social care professionals who know the individual and their circumstances will inevitably be more pertinent and accurate than a one-off assessment by a health professional who will typically not know the claimant or have dedicated expertise in their condition.

Introduction

1. Few conditions are as devastating as motor neurone disease (MND). It is rapidly progressive in the majority of cases, and is always fatal. Patients will, in varying sequences and combinations, lose the ability to speak, swallow and use their limbs; the most common cause of death is respiratory failure. Most commonly the individual will remain mentally alert as they become trapped within a failing body, although some suffer from dementia or cognitive change. There are about 5,000 people living with MND in the UK. Half of people with the disease die within 14 months of diagnosis. There is no effective curative treatment.

2. The MND Association is the only national organisation supporting people affected by MND in England, Wales and Northern Ireland, with approximately 90 volunteer led branches and 3,000 volunteers. The MND Association’s vision is of a World Free of MND. Until that time we will do everything we can to enable everyone with MND to receive the best care, achieve the highest quality of life possible and to die with dignity.

3. This submission covers selected areas of the call for evidence; we have no comment to make at present on those areas not addressed.

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.

4. We do not accept the Government’s arguments for reforming DLA. The benefit is not confusing and complex: among people with MND, 93% say that they feel they understand it, the highest figure for any benefit.
5. The benefit is not ‘out of control’: increased uptake is a sign of a successful
benefit that is well understood among the people who are entitled to it. We would
like to see the Government make a clear statement that it intends to maximise
uptake of all benefits, so that people who need them do not miss out.

6. We would, however, welcome simplification of the form and process by which
applications are made, as despite high levels of understanding many people with
MND find this difficult.

The extent to which overlaps in funding exist, particularly with local authority and
NHS funding, and including for people in residential care or hospital.

7. We do not perceive any current overlaps in funding between NHS, social care
and benefit provision: each exists for a distinct purpose and this is generally well-
respected in how they are provided in practice. We made this point in our
submission to the Dilnot Commission on the funding of social care, and were
pleased to see its final report draw the same conclusion.

8. We acknowledge that such an overlap has been presented as a justification for
the Government’s proposal to deny the mobility component of DLA to people
living in residential care funded by local authorities. We do not believe that any
argument along these lines bears scrutiny.

9. It has been argued variously that there is a funding overlap with social care,
although this is not the case (‘Don’t Limit Mobility’, Mencap et al. November
2010), and that removal aligns the position of people in residential care with that
of people in hospital, although as care homes are not centres for medical
treatment this is not a legitimate comparison.

10. We are concerned, however, that the current proposals for PIP, including the
draft regulations published by the DWP, risk introducing an overlap between PIP
and social care. There appears to be a significant mismatch between the
Government’s stated policy intention in respect of PIP and the formulation of the
draft criteria. While PIP is intended to focus on what the individual is able to do,
and to support them both to live independently and to engage in wider activities
in the community, the draft criteria examine only the basic essentials of living:
washing, dressing, moving around and so on – exactly the things that social care
is meant to cover. In order to meet the stated policy intention underlying PIP, and
to avoid a novel and dangerous overlap with social care provision, the
assessment criteria must be re-drafted to examine barriers to independent living
and social engagement.
Whether automatic entitlement should apply to people with some conditions or impairments and whether some people should receive awards for indefinite periods.

11. It is in many senses positive that the Government is keen to move away from a medical model of disability towards a more social one, and to focus on the individual rather than their illness or disability.

12. For MND, however, this can be somewhat problematic: it is a serious and terminal illness. Setting it within a social model is therefore a challenge, when the needs arising from it are so often highly medical. We therefore do not believe it is appropriate to disregard all medical considerations from the assessment of PIP: some medical diagnoses should lead to automatic entitlement, or at the very least generate a significant weighting within the assessment in favour of entitlement. MND should clearly be one of these conditions.

13. Any award to a person with MND should be for life: it is a medical impossibility for their condition to improve. The award should only be varied if it is first given at the standard rate and needs to be increased to the higher as their condition deteriorates. After that point, anyone with MND should be exempted from reassessment, as it would serve no purpose.

14. It is worthwhile to reflect on the name of the proposed new benefit in this context. While it is right that the benefits system should support disabled people to live as independently as possible, it must not be overlooked that people with MND will inevitably lose their independence, and subsequently their lives, as a result of their illness. Any benefit that fails to recognise this will fail people with MND.

The implications of a six month qualifying period.

15. We recommend that the qualifying period be aligned for both PIP and Attendance Allowance at three months. Under the proposed change to six months, combined with the proposed new medical test, a person with MND may not develop sufficient disability to qualify for the benefit at all until some time after their diagnosis.

16. Let us take the case of a person with MND whom a neurologist declines to support for Special Rules, in the expectation that they might live another twelve months or so. The individual goes on to develop a level of disability judged to qualify for PIP three months after diagnosis and subsequently dies within the next six months, their condition having deteriorated slightly more rapidly than their neurologist had anticipated. This would be among the poorer outcomes of an MND diagnosis, but is by no means unheard-of. This person will have been denied support either entirely, or until very shortly before their death.
17. Such problems will arise because of both the longer qualifying period and the inadequacies in the Special Rules system. Although MND is a terminal illness, and the Special Rules system nominally exists for those who are terminally ill, it often does not work for people with MND. The definition of ‘terminally ill’ as meaning a prognosis of six months or less is particularly awkward for people with MND: half of people with MND die within 14 months of diagnosis, so while only a modest proportion survive for fewer than six months after diagnosis, many more die shortly after this period. Unsurprisingly therefore, fewer than half of people with MND report being able to access the Special Rules scheme despite all being terminally ill.

18. We believe that the Special Rules system was intended to extend protection and support to people with devastating, terminal diagnoses such as motor neurone disease, and urge that it be amended to meet their needs and correct a long-standing failing.

19. This might be achieved in several ways. Changing the threshold from a prognosis of six months to twelve months would be the simplest, and would open up Special Rules to people with MND except those with the slowest-progressing forms. This extended threshold might be applied only to specific diagnoses, where progression is often rapid but difficult to predict in any given case.

The design of the PIP assessment, including: the assessment criteria and design

20. We are deeply concerned that the present draft criteria will, if implemented without substantial revision, badly let down people with MND. Nearly all of the various descriptors within the draft criteria could apply to a person with MND at different stages: while not every person with MND will lose the motor function in every part of their body, most will develop many of the impairments described in the draft criteria, including the cognitive ones in some cases. As a result, whether people with MND are granted the benefit will depend on the largely haphazard question of their exact condition when they are assessed.

21. We are concerned that under the current proposals, people with MND could be incentivised to wait until well into their illness before claiming PIP, in order to be sure of success. Alternatively, they will apply, be failed under the assessment, and have to go through an appeal process: by the time this is complete their condition will in many cases have deteriorated to the point where they would have passed an initial assessment anyway.

22. One of our key recommendations to the Government when they consulted on PIP was that assessment should be anticipatory: that is, it should take into account the future progress of MND, not just its progress to date at the time of the assessment. Both the regulations and the explanatory notes published by the
DWP appear to rule out any form of anticipatory assessment. For instance, the explanatory notes say:

*When considering the definition of disabling effects the risk of an event occurring alone is insufficient, there has to be actual functional impairment or evidence that the risk will occur.*

23. MND is a complex and unpredictable disease: it is not possible to provide evidence that a particular motor function will inevitably be lost; rather, it is prudent to plan on the basis that any and all motor functions could be lost, in the knowledge that some certainly will, even though it is impossible to say which, in what order or how quickly. The proposed approach does not appear to allow for sensible anticipatory assessment of this kind.

24. The proposal for regular reassessments is also pertinent. MND often progresses so rapidly that unless the reassessments are very regular indeed, they will fail to keep up with changes in the individual’s condition. The only alternative to anticipatory assessment would be to set a very short review interval, perhaps no greater than two months, although this would be very expensive for the Government. Anticipatory assessment is clearly the preferable option.

25. We also recommend that claimants should be able to trigger an urgent review, so that a deterioration in their condition can be quickly taken into account and their entitlement revised accordingly.

The extent to which aids and appliances should be taken into account in the assessment

26. We have made clear to the Government that we do not support the proposal to take aids and adaptations into account. Wheelchairs and other aids are often provided inappropriately slowly to people with MND, and also require modification over the course of the person’s illness: they do not solve all mobility problems, and even the help they do provide can be temporary, as the person’s condition deteriorates further. Adaptations to people’s homes are also extremely unreliable and slow: it is not uncommon for someone with MND to obtain a wheelchair but be unable to use it because the necessary adaptation to their home has not been made.

27. Taking aids and adaptations into account would therefore introduce such massive potential for error into the assessments that it would inevitably lead to many unjust decisions, and many more appeals – the costs of these errors would be enormous, both to the claimants affected and to the taxpayer.

28. The descriptors relating to mobility do not address the barriers that a person with MND might face even when they do have appropriate mobility aids: they assume,
for instance, that a journey (whether simple or complex) is feasible to begin with – in reality, a person with MND will often be reliant on the accessibility of public transport, or the availability of a car adapted to accommodate a wheelchair. They also assume that “moving” will inevitably be on a flat surface, and do not assess whether a claimant can go up stairs.

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.

29. We have identified several issues relating to the delivery of the assessments, particularly in light of experience with the Work Capability Assessment, on which we recommend that the Committee seeks further clarification from the Government.

30. Firstly, while the proposed outline of the process states that most individuals will attend a face to face assessment at which they will have the opportunity to explain their circumstances, experience of the Work Capability Assessment has shown that independent assessors can often be keen to take claimants through a defined set of questions without entering into a proper discussion. How will the Government ensure that this is not repeated for PIP assessments?

31. Secondly, what weighting will be attached to the additional evidence considered by decision-makers, relative to the findings of the assessment? Where complex neurological conditions such as MND are concerned, expert testimony from health and social care professionals who know the individual and their circumstances will inevitably be more pertinent and accurate than a one-off assessment by a health professional who will typically not know the claimant or have dedicated expertise in their condition.

32. Finally, if the assessment is conducted by an ‘independent’ assessor, as the Government proposes, does that mean that the task of conducting the assessment will be outsourced? In discussions about Employment and Support Allowance and the WCA, the Minister for Employment has recently emphasised that the contractor, Atos, is merely performing a service for the department, and that Atos should be considered part of the DWP for the purposes of improving the process. We therefore hope that an in-house assessment programme will be one of the options considered by DWP for PIP: even if an external contractor has the virtue of being ‘independent’, this advantage has been more than outweighed in respect of ESA by the poor quality of Atos’s delivery, and we see no reason why a programme of assessment run (at arm’s length if desired) by DWP should not be at least as effective.

September 2011
1. About Every Disabled Child Matters
   1.1. Every Disabled Child Matters (EDCM) is the campaign to get rights and justice for every disabled child. We have been working to raise the political profile of disabled children and their families, and campaigning to get the services and support they need to lead ordinary lives.

   1.2. EDCM is a consortium campaign with four members operating as equal partners, Contact a Family, Council for Disabled Children, Mencap and Special Education Consortium. Between them, the campaign partners work with and represent all of the 770,000 disabled children and young people in the UK, and their families. EDCM is a member of the End Child Poverty Campaign and the Disability Benefits Consortium.

2. DLA and Disabled children
   2.1. Disability Living Allowance (DLA) is a vital financial resource to help families with disabled children meet their high unavoidable costs, such as transportation and personal care. DLA is a non-means tested benefit that is accessed by families’ right across the income spectrum. The National Network of Parent Carer Forums in their submission to the Government’s consultation on DLA stated “we regard DLA as an essential component to enabling the families of disabled children to live ‘ordinary lives’.” A recent survey by the Family Fund outlined some of the additional outgoing costs families with disabled children have to meet. Household’s reported extra costs of up to £400 per month relating to their child’s disability, with many households having extra costs for laundry, heating, hot water, clothing, food and household adaptations.

   2.2. However despite this non-means tested benefit for families with disabled children, many still struggle to meet their additional costs. A recent Contact a Family survey of families with disabled children found that more than a third (34%) of respondents have fallen behind with repayments, most for credit cards and loans as well as utility bills. This survey also found that almost a quarter (23%) of surveyed families were going without heating and one in seven (14%) surveyed families are going without food.

   2.3. It is imperative that any reforms to DLA for children do not result in families with disabled children being financially worse off. These families are already disproportionately likely to live in poverty. EDCM is concerned that any reduction in financial support for these families will result in higher rates of poverty amongst families with disabled children.

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1 EDCM (2011) Breaking down barriers: making work pay for families with disabled children
2 Contact a Family (2010) Counting the Costs: The financial reality for families with disabled children
3. Personal Independence Payments (PIP) and disabled children

3.1 On the face of the Welfare Reform Bill it is not clear how the Government intends to reform DLA for under 16s. This has resulted in debate in the Commons stage of the Bill focusing on the system for working age adults. EDCM is concerned that the lack of debate and the legal implications of the Bill may result in the creation of a new benefit system for disabled children without proper debate and parliamentary scrutiny. EDCM believes that there is a valid case for the design of PIP to be different for under 16s, we set out below our reasons for this. In the past the disability benefits system has been designed around the recognition that there is a need for the system to work differently for children, for example children were able to receive DLA for the first 84 days in hospital, whereas for adults this stops after 28 days.

3.2 These concerns on the lack of clarity on the design of PIP for under 16s were addressed to some extent by the Government’s response to its consultation on DLA reform where it confirmed:

- The Government intention is to extend PIP to under 16s as part of the welfare reform programme. The consultation response stated: ‘Clearly, extending Personal Independence Payment to children would be the right thing to do.’
- However, PIP will not be extended to include disabled children in 2013/14. The Government will only look at transferring children onto PIP when they can ‘demonstrate it provides a fairer, more objective and more transparent alternative to the current arrangements’.
- The Government recognises that a specific assessment should be developed to ensure that the needs of children with long-term health conditions or impairments are properly considered.
- That under 16s will not be moved onto PIP without a public consultation and any decisions made will be subject to Parliamentary scrutiny.

3.3 EDCM welcomes the Government’s assurances that there will be some debate and scrutiny of any changes to DLA for under 16s. However we seek a clear timeline against which the Government plans to migrate children onto PIP. A clear message on the timescales for migration would allay the fears of parents of disabled children about the impact of the reform, which have been exacerbated by the lack of clarity on what the changes mean for them. We also have concerns about the implications of reform on disabled young people turning 16 after 2013 – which we go into more debate about in section 4. We conclude this submission looking at how we believe PIP should work for children under 16 when and if they are eventually migrated onto it.

4 Disabled Children and the Qualifying Period

4.1 “When my son was diagnosed at 14 weeks with a rare liver condition we spent a total of nearly 18 months in hospital. During this time I lost my home, my business, all my savings, as I had to pay for accommodation, food etc for my other son as well as myself whilst we supported my youngest son in
4.2 The Government has stated that they are planning on increasing the qualification period before adults are entitled to PIP from three months to six months. It is currently unclear what the qualifying period for PIP would be for under 16s. In a debate on this issue in the Commons committee stage of this Bill the Minister for Disabled People stated “If we were minded to look at a way in which to vary the qualifying period for children, we would consider it carefully.”

4.3 The importance of early intervention and support for families with disabled children is well documented. When a child has a diagnosis of a severe and enduring disability, particularly one which is life limiting or life threatening, the impact on their family’s financial circumstances is likely to be immediate. Having a premature or sick baby costs the average parent an extra £189 per week while their child is in hospital, with the average total cost reaching £1,885, with parents typically having to fund travel to and from hospital and food away from home, as well as dealing with loss of earnings. There are similar issues for children who develop sudden-onset conditions that require them to receive specialist medical treatment. For example, children with cancer tend to receive treatment straight away and along with this, begin the immediate costs associated with a child in hospital.

4.4 A delay of six months before support is provided would deprive the family of essential early support, and would consequently place them at a disadvantage when they are in greatest need. We would like to see disabled children being entitled to DLA from the point of diagnosis. This recommendation is in line with a cross party report published in 2006 following on from Parliamentary Hearings on Services for Disabled Children which recommended that the “Government should also consider waiving the 90 day eligibility period where children have additional time-limited care or mobility needs as a result of medical intervention.”

5 Adaptations and Aids

5.1 NHS wheelchairs are not always very good and some families cannot afford to pay extra. I think it’s good Whizz-Kidz are involved in providing wheelchairs as they have a lot of special knowledge about children and wheelchairs and provide training for disabled children. I went on one of their courses and it was really helpful. Adam

5.2 EDCM is also concerned about the Government’s proposals on adaptations and aids. To financially penalise families for having suitable equipment would be extremely damaging. It would reduce families’ ability to contribute towards aids and adaptations that meet their child’s wider well-being needs and that help that child live a more independent and ordinary life. It would also not take into account that having an aid or adaptation does not create a completely

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3 Case study from Stop the DLA Takeaway, Contact a Family and the Children’s Trust Tadworth (2010)
4 Bliss (2007) Too little, too late?
5 Parliamentary Hearings on Services for Disabled Children, Full report, 2006
6 EDCM (2009) Disabled Children and Health
accessible society and that to allow disabled children to live ordinary lives many families will still incur additional costs regardless.

5.3 Additionally, the reality faced by any family or individual who rely on the use of equipment designed to support independence or mobility is like any other type of equipment – and can and often does break down. We therefore do not think that it is appropriate to include adaptations and aids in an assessment for disability costs benefits.

5.4 The ability to use aids and adaptations cannot be considered as a constant within a child’s life. Children are much more likely to require changes in equipment as they grow or their needs change. At present, families with disabled children face significant delays in receiving the aids and adaptations they need. Recent research from Children and Young People Now\(^7\) showed that children frequently wait ‘more than three months to be assessed and a further four months to finally receive their equipment.’ As a result, children who have been assessed as being mobile because of the use of a wheelchair for the purposes of DLA, might subsequently require a new wheelchair but be unable to access one for up to seven months.

6 Mobility Component of DLA

6.1 “The college currently requests a contribution towards the cost of transport. This payment contributes towards the cost of transport for activities outside of the curriculum. This includes, but is not limited to, visiting leisure facilities (for example, swimming pool and cinema), outings during the evenings and weekends (such as a trip to the coast), going shopping for personal items and accessing local groups such as youth clubs. The alternative would be to use public transport. This would be difficult as the college is not on a bus route…The activities carried out in the student’s free time are chosen by the students and if we were unable to request a contribution to the cost of transport from the DLA mobility component, our student’s choices would be severely restricted\(^8\).” Specialist residential college

6.2 EDCM is concerned by the Governments proposals to remove the mobility component of PIP from disabled people living in residential care homes, schools and colleges. The justification given by Government for the removal of the mobility component of PIP from disabled people living in residential homes is that of double funding – i.e. transport is provided by the facility (school or college) themselves. However, the evidence – cited in the example above - suggests that this is not the case. Even where transport is provided by the education provider, it is often restricted to provision at the start and end of term. No extra provision is factored in for visits at weekends or for the child when they are at home during the holidays.

6.3 When the Government originally announced this proposal, in the Comprehensive Spending Review on 20 October 2010 they stated that the removal of mobility benefit would apply to all DLA and PIP claimants, living in

\(^7\) Children and Young People Now (26 July 2011) Children endure seven-month wait for wheelchairs

\(^8\) Mencap et al (2011) Don’t Limit Mobility
local-authority-funded residential care, from October 2012. The Government upon the introduction of the Welfare Reform Bill delayed the implementation of this policy until April 2013 and attached the changes just to PIP claimants. This means until disabled children are moved onto PIP they will be able to continue to receive the mobility element of DLA when living in a local authority funded school.

6.4 However EDCM is concerned about how this policy will work for disabled children once they are moved onto PIP. We are also very concerned about the implications of this policy on disabled young people living in residential college and further education settings. For all young people aged 16 – 25 the ability to get around independently is vital in leading the ‘ordinary life’ of a young person and for developing life skills leading to independent living later in life. We know it is also the Government’s intension for disabled young people to be able to live an independent adult life as stated in the Green Paper on SEN and Disability “Our goal is for disabled young people and young people with SEN to have the best opportunities and support so that as far as possible they can succeed in education and their careers, live as independently and healthily as they are able to and be active members of their communities”. It would be devastating for financial support for mobility to be withdrawn from these disabled young people just as their adult lives are beginning.

6.5 Removing the mobility component of PIP from young people, and in the future potentially from children, severely restricts their ability to live independent lives. We also believe that it is in contravention of Article 31 of the UN Convention on the Rights of the Child, which covers young people up to the age of 18, which states:

1. States Parties recognize the right of the child to rest and leisure, to engage in play and recreational activities appropriate to the age of the child and to participate freely in cultural life and the arts.
2. States Parties shall respect and promote the right of the child to participate fully in cultural and artistic life and shall encourage the provision of appropriate and equal opportunities for cultural, artistic, recreational and leisure activity.

6.6 Disabled children and young people should be able to spend time with their families and to lead an ordinary family life. They should also be able to spend time with their friends outside of school. This is not possible for many children and families without financial support due to the high unavoidable costs related to travel and leisure activities for people with disabilities.

6.7 We are concerned that if the mobility component of PIP is withdrawn from disabled young people, it will not be possible for them to leave their residential setting when their families visit, to spend time with their friends or to take part in community activities. This means they will essentially be trapped in their

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9 Department for Education (2011) Support and aspiration: A new approach to special educational needs and disability - A consultation
10 United Nations Convention on the Rights of the Child
7 PIP and Disabled Young People turning 16

7.1 The transition from childhood to adulthood is a notoriously difficult time for many disabled children, with many parents describing it as like ‘standing on the edge of a cliff, about to fall into a black hole’¹¹. Whilst we welcome the Government’s decision to have a different commencement date for children and working age adults for PIP we are concerned about the impact that interface between the two systems may have on disabled young people as they turn 16 in 2013 and beyond. EDCM has been concerned that the policy as it is written may result in disabled young people when they turn 16 ‘testing out the new system’. This issue was raised in the Common’s committee stage and the Minister for Disabled People commented:

7.2 “The honourable member for Stretford and Urmston talked about children turning 16 shortly after the introduction of PIP, and made the assumption that they would be the first to go through the new assessment. I can understand why she assumed that, but I would like to clarify the matter for her. The migration strategy is a very detailed piece of work, in terms of who would be migrated at which point. There are very important equality issues tied up with all those matters, and they are being looked at carefully, but we obviously want to consult disabled people, their families, and user-led organisations to get that important aspect of the Bill right. We would also include organisations representing disabled children. So I urge the hon. Lady not to make the assumption, at this stage, that 16-year-olds would be the first to go through the new assessment, because that may or may not be the case. We want to look at it in great detail.”

7.3 EDCM would like the Select Committee to seek further clarity on what safeguards the Government will be providing to ensure a smooth transition for disabled young people turning 16 in 2013. In order to mitigate the impact of disabled young people being the first people to ‘test out the system’ we believe that disabled young people aged 16 – 25 should be the last people to be assessed for and moved onto PIP from DLA under the migration strategy. This would mean that 16 – 25 year olds were not considered new customers for PIP, and would continue to receive DLA, until the system had been thoroughly tested.

September 2011

Written evidence submitted by Mental Health Advocacy Project (West Lothian) (PIP 27)

The West Lothian Service Users Forum (WLSUF) is coordinated and facilitated by the Mental Health Advocacy Project (West Lothian). The Mental Health Advocacy Project consulted West Lothian Service Users Forum on the proposed changes from DLA to PIP. The following is the Forum members’ response to the proposed changes from Disability Living Allowance (DLA) to Personal Independence Payment (PIP). Forum members are all mental health service users living in West Lothian, most of whom are in receipt of DLA. Forum members hope that their feedback to this consultation is taken into consideration as DLA changes to PIP.

1 “Why Disability Allowance needs to change”

“We want to find out”

“If people understand Disability Living Allowance”

Mental health service users in West Lothian already in receipt of DLA say that this benefit is available to people who are disabled due to the impact a mental illness has on their capacity to live independently in the community. Individuals perceive that the benefit can be used to enable them to do a number of things such as:

- “To buy in extra help to carry out daily living tasks such as kitchen/bathroom hygiene services,”
- To help with medication as some forget to take the medication that helps to keep them well
- To buy easy to cook meals or convenience food as some find loss of concentration and poor motivation a problem when it comes to planning, preparing and cooking a meal.
- To help to access help with travel when travelling alone is very difficult”
- To access help to help with communications, such as letters, appointments, meetings and socialising”.

“Why Disability Living Allowance is costing more than it used to and why more people are claiming it”.

WLSUF say that “when the benefit was first introduced many people who experience mental illness did not know about DLA, it has taken many years for people to realise that they may qualify for it. Initially the lengthy form put some people off but with the help of welfare advice services many people claimed, who may not have if left to complete it on their own”.

“How well the system is working when it comes to deciding if people should get DLA, or should carry on getting it for a long time.”

WLSUF reported that there are problems in this area and sometimes people have to go through the appeals process when perhaps they should not – maybe they just missed something out in the long and complicated application form. The appeals process brings added problems for people who experience a mental illness as they have to attend a tribunal hearing. The tribunals are conducted in Edinburgh, meaning that people living in
West Lothian have to travel some distance to attend. The stress of this for people who experience a mental illness can exacerbate their symptoms. Mental health services do not always have the capacity to provide support to attend such hearings. WLSUF say “it would be very helpful if hearings could be held locally as travel is a very real difficulty for many people with a mental illness. An increase in face to face meetings with the authorities is likely to engender more stress, fear and worry all things that impact negatively upon well being”.

WLSUF also say that it is a relief to some people to be awarded DLA for a long time as mental illness can be life long and the process of reapplying can be very stressful. It may be better if it were acknowledged that some disabilities can be life long although this will differ from person to person even if they have the same diagnosis.

2 “What cutting the money spent on DLA will mean for people.”

“We want to find out”:

“What will happen if only people with the greatest need can claim.”

WLSUF say that there are people who are currently in receipt of DLA who may not be perceived as having the greatest need but who’s quality of life would deteriorate drastically if the benefit were to be made unavailable to them. WLSUF are concerned that if quality of life deteriorates the impact upon services would increase which may prove equally costly. WLSUF say that DLA: promotes independent living, helps to reduce the need to rely on services, and that this should not be underestimated.

“What difference it will make to change to just 2 rates – higher and lower- in the ‘daily living’ part of this benefit.”

WLSUF are unsure about this – many people who experience mental illness are currently on the middle rate. This would not pose any real difficulty as long as income does not reduce as people are already committed to using their DLA for the intended purpose of living independently. Any reduction for individuals is likely to compromise independence and impact on services. There is a feeling however that many people will see a reduction in their DLA should they be moved from middle rate to the lower rate. The uncertainty at the moment is engendering a lot of unnecessary stress and worry for people who do not cope too well with such additional worries. Also for example the consequences of the proposed changes to DLA may affect qualification for a bus pass in West Lothian as people who experience mental illness should be in receipt of middle rate care component to qualify. There are many implications for people that need to be considered to avoid increasing the problems faced by people who experience mental health problems.

“How many people who now get DLA will not be able to get the new Personal Independence Payment?”

Depends upon what the government come up with however WLSUF are keen to ensure that any changes made do not impact negatively upon people who experience mental illness as they feel that this group are particularly vulnerable citizens who may be considered to be
one of the most marginalised groups in our society, many of whom rely on DLA to help them to live independently in the community.

3 “What other help disabled people and those with a long illness get, for example from local councils or NHS”.

“This includes people in residential care and in hospital”.

WLSUF are of the opinion that services are stretched to maximum and they see less help being available in the community to them than there was a few years ago.

4 Who should get Personal Independence Payment (PIP)

“We want to find out what you think about”:

“Whether people with some illnesses or disabilities should get PIP automatically”

WLSUF say that this may be good but how do you apply this in practice. How can authorities measure disability/diagnosis? The impact of how mental illness affects people may be very difficult to measure in an equal and fair way.

“Whether some people should get PIP for the rest of their lives instead of having to have reviews”

WLSUF say that being awarded PIP for life may: reduce the stress of having to complete complicated forms, remove the requirement to attend reviews often miles away from where you live which is very difficult for some people, reduce the fear of losing income. This would enable people who experience severe mental illness to get on with their lives without the constant fear of loss of income.

“What will happen if people who apply for PIP have to wait 6 months before they get it”.

WLSUF say this is not acceptable, shouldn’t be making the most vulnerable in our society wait for something like this, the only point of this is to save money. Saving money from the wrong people, disabled people have enough to contend with without facing unnecessary delays in payment to help with their independence”.

5 How PIP will lead on to other benefits.

Getting PIP will mean people can apply for other benefits like Carers Allowance and the Motability Scheme.

“What about bus passes, council tax reductions/exemption as this applies at the moment. Many people who experience mental illness live isolated lives and have no carer so this would not necessarily help such people.” DLA is used to help people to get the help they need independently of any family/carers which is really important in promoting independence”. 
6 How will people be tested to decide who gets PIP.

**We want to find out how the government can ensure that the system is fair to:**

**People with mental health problems**

WLSUF are pleased that the government are looking at how they can operate a fair system.

WLSUF say “people who experience mental health problems frequently experience (as well as the symptoms of illness): social isolation, difficulty using public transport, communication difficulties, difficulty taking medication, problems with self care, difficulties planning preparing and cooking meals, difficulty keeping structure in their day, difficulty with concentration and motivation, difficulty interacting with those both familiar and unfamiliar to them, and difficulty accessing services. We feel these factors must be considered if the system is to be fair to people with mental health problems. We need DLA to help to keep us well, among the obvious help it gives us it also helps to give us a social life which helps to promote structure in the day – people underestimate the need for us to have a social life. Social isolation is very bad for us, can make you feel suicidal”.

WLSUF say “the government need to listen, consider properly and act on what we and other charities like SAMH are saying about the needs of people with mental health problems

“People whose problem sometimes gets better but then sometimes gets worse again.”

WLSUF say that this is typical of some mental health problems. Fluctuating health can impact severely upon quality of life. The important things in life such as income need to be constant to allow people to live without the worry of having to adapt constantly to change. Also the benefit system needs to be flexible enough to allow us to come off benefits when they are not needed but to reclaim benefits in an easy way when they are needed. The present system is so complicated it can put people off trying to become more independent. The proposed 6 month wait for claiming DLA is unacceptable, will increase poverty and will push people further into becoming disadvantaged and marginalised members of society.

7 Who is going to decide who gets PIP

**We want to find out:**

**How the organisation who will do the test will be chosen.**

WLSUF have serious concerns about the system in place that carries out the medicals for ESA. WLSUF have had quite a number of reports from mental health service users concerned about the company ATOS, the test that they use and the way it is carried out. WLSUF say the tick box system used by ATOS is unsuitable in assessing mental health adequately, it does not provide a clear picture of the nature of mental illness and the impact it has on a peoples lives. The current ESA test offers no opportunity to explain how the
illness affects daily life, also people who experience mental illness are not always sure or lack insight into how it affects their own daily life and are likely in their answers not to explain difficulties accurately. People who experience mental illness cannot always verbalise how their illness affects them/do not wish to disclose their problems even to their doctors/consultant. It is very difficult to explain the extent to which mental ill health affects our lives, sometimes it is easier to say everything is fine when that can be far from what is actually the case. It is essential that anyone assessing us has a good knowledge of mental health problems and that the test allows a full explanation of the problems endured by people who experience mental health problems. WLSUF say that many people need support from the services to attend such tests but the services not always have the capacity to help with this.

"Which staff will decide who gets the benefit?"

WLSUF say “different staff may reach different conclusions, they may have no knowledge of mental illness and how it affects people.”

“How the assessment for PIP will fit in with assessments for other benefits?”

We are constantly being assessed – by the NHS, by Social Work, by the DWP for ESA for JSA for DLA, by tenancy support providers, surely this could be better organised and more efficient.

9 What the Department for Work and Pensions needs to do to make sure that people understand the changes.

People need to be provided with clear information about the changes. People need to know whether they will qualify for high or low rate and they need to know what the rates are in terms of income so they can at least access help to re organise their finances if need be. People are extremely worried by the whole benefit reform, many in West Lothian believing they will be significantly worse off.

10 What is going to happen to help people adjust to the new system.

WLSUF say “because we don’t know the detail of the new system we don’t know what will be needed to adjust to the new system”.

September 2011
Written evidence submitted by CLIC Sargent (PIP 28)

Introduction and Summary

1.1. CLIC Sargent, the UK’s leading cancer charity for children and young people, welcomes the opportunity to respond to the Select Committee’s inquiry into the replacement of Disability Living Allowance (DLA) with Personal Independence Payment (PIP). CLIC Sargent is also a member of the Every Disabled Child Matters campaign and the Disability Benefits Consortium and so we also support these submissions.

1.2. We welcome the Government’s intention to retain the principle of DLA as a non-means tested cash benefit contributing to the extra costs incurred by disabled people. However, we have some serious concerns that the introduction of PIP will significantly disadvantage young cancer patients and their families.

1.3. The two key issues that this submission focuses on are the potential negative impact on 16-18 year olds and the extension of the qualifying period. Whilst this submission focuses on the proposed impact of changes to DLA, we believe this must also be seen in the context of changes to other benefits which are likely to negatively impact on young cancer patients, including the removal of the youth condition of Employment and Support allowance and changes to disability premiums within Child Tax Credits or Income Support under the Universal Credit.

1.3.1. Impact on 16-18 year olds1 – The Government has confirmed that the reform of DLA for under 16 year olds will be taken forward separately and will be subject to a further public consultation and Parliamentary scrutiny which is welcome. However, CLIC Sargent is concerned that the PIP system will not meet the unique needs of young people aged 16-18 who will be treated the same as adults despite being much less likely to have financial independence and having access to fewer benefits. More importantly, this should be seen in the context of the Government’s own plans to concurrently raise the participation age2 and the Government’s SEN and Disability Green Paper’s vision for a coordinated system of assessment and support from birth to age 25. We believe there are many arguments to consider the reform of the system for 16-18 year olds, and arguably 16-24 year olds, alongside the reforms for under 16s, recognising the unique needs and situations of these age groups.

1.3.2. Extension of the qualifying period3 – The extension of the qualifying period from three to six months will particularly disadvantage those with sudden onset conditions, including cancer. Treatment for young cancer patients often starts immediately after diagnosis but under the new PIP many will not receive any financial support until well into six months after diagnosis. Given that treatment necessarily requires significant travel to a specialist treatment centre often many miles from home, this will mean young cancer patients and their families will have already incurred significant additional costs by this point, often combined with a loss of income by either the young person and / or their parents. The Government’s DLA consultation response acknowledges that this extension ‘may

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1 Relevant Clause – 91 Regulations
2 The Government plans to raise the participation age in 2013 (to age 17) and 2015 (to age 18). This means that those aged 16-18 are almost certain to still be education or training and are unlikely to have an independent income.
3 Relevant Clause – 79 Required Period Condition: further provision
well attract additional costs\textsuperscript{4}, but suggests that these may be covered through other mechanisms such as NHS travel costs; unfortunately these are either means-tested or only available to people out of work, meaning that many cancer patients could be ineligible for these but could still be eligible for PIP as a non-means tested benefit which people can apply for regardless of their employment status. \textbf{We would therefore like to see a change to the required period condition to a qualifying period of three months and a prospective test of nine months which would satisfy the Government’s requirement around the Equality Act definition of long-term disability.}

2. Background

2.1. Every day 10 families are told their child has cancer. Usually treatment begins straight away, but so do the side-effects of this treatment and the extra expenses families’ face following the diagnosis. And these costs, like the side-effects, will persist for the full duration of the child or young person’s cancer treatment, although it is in the first few weeks after diagnosis when the initial financial crisis hits as the patient is required to spend a significant amount of time either at hospital for tests and clinic appointments or as an inpatient.

2.2. A 2007 study found that 83% of families incur significant extra costs associated with their child’s cancer treatment with 68% of families experiencing worrying financial difficulties following diagnosis.\textsuperscript{5} This is coupled with parents often cutting back on working hours to spend more time caring for their child (9/10 parents surveyed do so), leading to decreased income. Despite this, DLA at present can be the only additional support families receive and the delay in receiving the benefit, both because of the existing qualifying period and processing time, already presents a challenge for most families and so doubling this time period will create even more hardship. Usually the children and young people with whom we work are eligible for the higher or middle rate care allowance and higher rate mobility allowance, demonstrating a high level of need.

2.3. We believe the proposed extension to the qualifying period will particularly discriminate against those with sudden-onset and fluctuating conditions such as cancer and is likely to remove eligibility altogether for those with shorter treatment periods.

\textsuperscript{4} Department for Work and Pensions (April 2011) \textit{Government’s response to the consultation on Disability Living Allowance reform}, p21

3. The impact on 16-18 year olds

3.1. We are pleased that the Government will be separately taking forward the reform of DLA for under 16 year olds and that this will be subject to a further public consultation and Parliamentary scrutiny. This is important to ensure that whatever system is introduced recognises the unique needs of children with long-term health conditions and impairments.

3.2. However, the Government appears intent on distinguishing between those of working-age (16-64 year olds) and those under working-age (under 16 year olds). Not only does this distinction risk a system where the unique needs of young people are not recognised by the system but this appears to jar with the Government’s own plans to raise the participation age, as well as running contrary to the vision set out in the recently published SEN and Disability Green Paper for a coordinated system of assessment and support from birth to age 25. The plans to raise the participation age will mean the majority of 16-18 year olds will still be in education or training, however the Personal Independence Payment system will categorise them as ‘working age’.\footnote{The Government plans to raise the participation age in 2013 (to age 17) and 2015 (to age 18). This means that those aged 16-18 are almost certain to still be education or training and are unlikely to have an independent income.}

The Department for Work & Pensions (DWP) has tried to challenge this argument on the basis that DLA (and PIP) is available to both those in and out of work, however, they themselves make reference to the fact that PIP will initially be for those of working-age in several key policy documents.

3.3. In terms of the services for teenagers and young adults with cancer (TYAs, 16-24 year olds), best practice NICE guidance recognises that: “very different issues arise depending on the age and maturity of the individuals whose needs are being addressed. Childhood and adolescence is a time of enormous change, physically, psychologically and socially, and this influences the different patterns of malignancy seen, their pathological behaviour, response to treatment and eventual outcomes.”\footnote{NICE (2005) Improving outcomes in children and young people with cancer, http://guidance.nice.org.uk/CSGCYP}

The guidance therefore recognises 16-24 year olds as a distinct group with specific social, psychological, and educational needs and details how services should best be organised to meet the needs of this group which is then verified as part of the peer review process. It is therefore critical that that the welfare system, on which many 16-24 year olds with serious health conditions rely for support, also recognises this distinction instead of relying on an outdated classification of working-age and non working-age.\footnote{Whilst we believe the case for considering a specific PIP system for 16-24 year olds has merit, the argument for 16-18 year olds is particularly strong and this is why this is the main focus of this submission.}

3.4. We would also highlight that the UN Convention on the Rights of the Child, ratified by the UK Government in 1991, states that a child “means every human being below the age of eighteen years”. The consultation document’s impact assessment states that “we recognise that many people who have become disabled earlier in life have had fewer opportunities to work or save for later life” – CLIC Sargent would argue that this applies to those aged 16-18. In addition, we do not believe this impact assessment nor the Bill’s impact assessments at present captures the potential disadvantage that the new system will put on those aged 16-18 in particular.
3.5. CLIC Sargent would argue that the best way in which to meet the holistic needs of young people with health needs would be to align and join-up the various systems of support, as envisaged by the SEN & Disability Green Paper. However, we recognise that creating a distinction in the disability benefits system for 0-16s, 16-18s, and 19-24 year olds may not be viable in the current financial climate. We do believe, however, that it is reasonable to argue that the system should make particular provision for 16-18 year olds, most of whom will still be in full-time education and financially dependent on their parents when PIP is introduced. Otherwise this group of vulnerable young people risks being some of the first to experience the PIP system which is unlikely to meet their unique needs given it is based on the needs of working age adults.

3.6. At present, CLIC Sargent is working with 489 16-18 year olds with cancer. Whilst we recognise that making age-appropriate provisions for this age group will cover those with other eligible health conditions and impairments, we do not believe this will impose a significant additional cost burden, particularly as this group of vulnerable young people would be covered by the adult system anyway were no changes to take place. DWP data suggests that there are currently 52,190 DLA claimants aged 16-17; there is no data for those aged 18 but we would posit that this would be around 30% more, bringing the estimated total to around 69,586. On the other hand, we believe there is much to gain by putting in place an age-appropriate system for vulnerable young people aged 16-18. We would argue specifically that the qualifying period must not be extended for 0-18 year olds, to reflect the additional costs and needs of a family looking after a child or young person with an eligible health condition or impairment.

3.7. The benefits system at present makes a number of distinctions based on age and there is a concern that those aged 16-25 face multiple disadvantages as a result of this, particularly in terms of the benefits available to them and their level of financial independence. We are therefore concerned that if the DLA / PIP system makes a distinction between those under 16 and those over 16, those aged 16-18 may fall through the gap. Case study evidence (one example included below) from our social workers suggests that young people with cancer are already treated less favourably than children with equivalent conditions and needs, with a much greater proportion

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9 The SEN and Disability Green Paper, Support and aspiration: A new approach to special educational needs and disability (Department for Education, March 2011), proposes the development of a single statutory assessment process and ‘Education, Health and Care Plan’ from birth to 25. This plan would cover education, health, employment and independence. The Government’s response to the DLA consultation confirms that the Government intends to consider how the single assessment process might be used to support claims for DLA and PIP.

10 Department for Work & Pensions (August 2010) Disability Living Allowance - all entitled cases Caseload (Thousands) : Age of claimant by Care Award Type [http://83.244.183.180/100pc/dla_ent/cnage/careawd/a_carate_r_cnaire_c_careawd_aug10.html](http://83.244.183.180/100pc/dla_ent/cnage/careawd/a_carate_r_cnaire_c_careawd_aug10.html)

11 For example, in the assessment phase, Employment & Support Allowance (ESA) claimants under the age of 25 receive a significantly lower amount than those over 25. There are also different eligibility rules for students wishing to claim ESA. In addition, Jobseeker’s Allowance and Income Support can usually only be claimed by over 18s.

12 For example, young people with cancer are much less likely to be awarded DLA than younger children with equivalent diagnoses and side effects.

13 On financial independence, young people as a whole are less likely to be financially independent that adults (who have had more time to save and get a job) but also are much less able to enter the job market, as evidenced by record rates of youth unemployment. This difficulty is compounded for those young people with health conditions and / or disabilities.
having to appeal to the get amount to which they are entitled, and our fear is that this will be exacerbated under PIP. This reform presents the opportunity to address these distinctions and to seek to minimise the number of transition points faced by young people across the various support systems. We would also urge caution on having two different systems for those under 16 and over 16 as this will create a particular cliff-edge for those young people with health needs and impairments during an already difficult period of transition. It is felt that at present the current DLA system works quite well in this regard. We are currently engaging with the DWP to seek to ensure the needs of young people with health conditions and / or disabilities are explicitly recognised in its migration strategy.

Case study: A 17 year-old boy and a 12 year-old boy were both diagnosed with Hodgkin’s lymphoma at the same time. In the DLA applications completed with support from their CLIC Sargent Social Care Worker the only difference was age – the illness, treatment and side effects were identical. However, when it came to the outcome of the award, it was totally different – the 17 year-old boy was refused DLA on the grounds that his health, wellbeing and the effects of treatment did not merit any award, whilst the 12 year-old was awarded high rate care and mobility due to the severity of treatment and illness. The only apparent difference is age. At present my colleagues and I are finding it more difficult to secure awards for the over-16s without having to appeal the benefit agency’s decision.

3.8. Crucially, and as demonstrated by the table below, DLA at present is the only benefit available to young people with a health condition and / or a disability whatever their situation. It is therefore critical that the new system is designed in a way to ensure this support continues and better meets the need of this age group.

<table>
<thead>
<tr>
<th>Benefits available to 16 to 18-year-olds with long-term health conditions who are:</th>
<th>(a) in employment</th>
<th>(b) unable to work as a result of their condition</th>
<th>(c) seeking work</th>
<th>(d) in full-time education</th>
</tr>
</thead>
<tbody>
<tr>
<td>Working tax credit</td>
<td>Yes</td>
<td>—</td>
<td>—</td>
<td>—</td>
</tr>
<tr>
<td>Employment and support allowance</td>
<td>—</td>
<td>Yes</td>
<td>—</td>
<td>—</td>
</tr>
<tr>
<td>Disability living allowance</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Jobseekers allowance</td>
<td>—</td>
<td>—</td>
<td>Yes</td>
<td>—</td>
</tr>
<tr>
<td>Income support</td>
<td>—</td>
<td>—</td>
<td>—</td>
<td>Yes</td>
</tr>
</tbody>
</table>

House of Commons Written Answer [52748], 16th May 2011

1.1. We believe the Government should consider the reform of DLA for 16-18 year olds alongside the reforms for under 16s and should also ensure that 16-18 year olds who
are still in education are not treated the same as other adults who are much more likely to have financial independence.\textsuperscript{14} It will be important to ensure, however, that those aged 16-18 who wish to have their benefit paid directly to them are able to do so, so as to not compromise their independence. At the very least, those already in receipt of DLA should continue to receive this until they turn 18. In addition, the migration strategy for PIP should make explicit reference to those aged 16-24, and specifically those aged 16-24 should be the last group to be assessed for and moved onto PIP. The extended qualifying period of 6 months must absolutely not apply to those aged 0-18 and ideally not for those aged 0-24.

2. Extension of the qualifying period

2.1. Clause 79 of the Welfare Reform Bill defines the ‘required period condition’ which an applicant must meet to be eligible for Personal Independence Payment. This is a qualifying period of 6 months and a prospective test of 6 months, i.e. an applicant must demonstrate they have had needs for 6 months and will continue to do so for a further 6 months.

2.2. This change will effectively double the current qualifying period of three months and CLIC Sargent is particularly concerned regarding the potential impact on those with sudden onset conditions, including cancer. Because those with sudden onset conditions, such as leukaemia, do not have a period of symptoms before diagnosis, their eligibility for the benefit will be counted from their diagnosis which could mean they do not receive any financial support until six months into treatment.

2.3. The current qualifying period of three months is already problematic for young cancer patients and their families, and our fear is that doubling this will push many into poverty, particularly when DLA is often the only form of financial support available. Normally the first three months are the hardest for the child, family and / or young person to deal with as they cope with the diagnosis and treatment. In addition, research has shown that increased costs are at their highest in the first year of treatment when travel to hospital, and time spent away from home, is at its maximum.\textsuperscript{15}

2.4. A recent survey showed CLIC Sargent’s social workers believe that increasing the qualifying period in this way will lead to 9 in 10 of patients suffering financially and over 60% thought that all of their clients would suffer as a result of this change. One social worker told us:

"It is hard enough for everyone to wait for 3 months and now all will have to wait 6 months before getting any money. This is a large portion of treatment with no money. Also, often people can manage for a few months because they may continue to be paid from work for a while, have savings or be entitled to several months full sick pay from work themselves. By 3 months this has all but run out, they are struggling to cover mortgage, costs of treatment, childcare costs for other children etc and hopefully by then DLA will have come through. Under proposed changes I can"

\textsuperscript{14} These issues could be discussed under the auspices of Clause 91 which gives the Secretary of State the power to make regulations, with a particular reference to different provisions for persons of different ages (4).

seriously see people losing their homes while their child is on treatment because they won’t be able to stretch covering costs for 6 months.”

2.5. Support sources such as the NHS travel costs scheme and Employment and Support Allowance, referred to in the Disability Living Allowance Reform consultation response as other options for support, are either means-tested or only available to people out of work. Cancer patients could be ineligible for these but could still be eligible for PIP which is a non-means tested benefit which people can apply for regardless of their employment status. Despite having an average round-trip distance to travel to hospital of 60 miles, the only additional financial support that most families will receive in addition to DLA are financial grants from charities such as CLIC Sargent.

2.6. Another of the arguments for the extension in the consultation response is to "align the benefit more closely with the qualifying rules for Attendance Allowance" which is the equivalent of DLA for those over 65. CLIC Sargent would point out, however, that whilst Attendance Allowance has a qualifying period of six months, there is no prospective test.

2.7. CLIC Sargent, along with Macmillan Cancer Support, believes that people with a sudden onset condition should be able to apply, and be assessed, for PIP as soon as their need arises. People with sudden onset conditions would still have to meet the eligibility criteria set-out by the assessment and demonstrate that their physical or psychological limitations are likely to last for one year. Therefore only those eligible will receive PIP and periodic reviews would make sure that people receive it only for as long as they need it.

2.8. Cancer can be a long term condition but support is needed from the outset. PIP is for people with support needs associated with long term disability or illness. This amendment therefore incorporates the Government’s proposal that PIP should only be available for people who have total period of need of one year. Whilst cancer patients frequently experience long-term effects as a result of their cancer, treatment or both, the time during initial treatment can often be when needs and costs are at their greatest. This is one of the key issues that was raised in the joint letter to Iain Duncan-Smith MP signed by 30 cancer charities which received significant media coverage and debate during the Bill’s Second Reading in the House of Commons. September 2011

17 All of those families with whom we work are offered an immediate CLIC Sargent grant of £170 to help with immediate financial needs. Additional grants are also available to some.
18 To align it with the definition of long-term disability in the Equality Act 2010 as an impairment which has lasted at least 12 months; where the total period for which it lasts is likely to be at least 12 months; or is likely to last for the rest of the life of the person affected.
1. About Law Centre (NI)

1.1 Law Centre (NI) is a public interest law non-governmental organisation. We work to promote social justice and provide specialist legal services to advice organisations and disadvantaged individuals through our advice line and our casework services from our two regional offices in Northern Ireland. It provides a specialist legal service (advice, representation, training, information and policy comment) in five areas of law: social security, mental health, immigration, community care and employment. Law Centre services are provided to over 450 member agencies in Northern Ireland.

1.2 We welcome the Government’s decision not to introduce the Spending Review proposal to withdraw the Disability Living Allowance (DLA) mobility component from people in residential care. There remain however other significant areas of concern with the proposals. In this evidence we outline the significant issues likely to be presented by the proposal to replace DLA with Personal Independence Payment (PIP), drawing attention to the Northern Ireland specific issues.

2. The Northern Ireland Context

2.1 DLA provides a weekly sum for the purpose of assisting a person with extra costs associated with a disability. Currently 185,457 people are in receipt of DLA in Northern Ireland. Of those 116,652 are of working age and therefore the group affected by these proposals. Northern Ireland has seen a growth of 2.6% in DLA recipients since 2009 (177,653).\(^1\)

2.2 ‘Mental health causes’ is listed as the most frequently occurring disabling condition in Northern Ireland with 41,381 people currently receiving DLA for this matter.\(^2\) A report by the Centre for Social Justice noted ‘the majority of people claiming illness-related out of work benefits do so on account of mental and behavioural disorders...this demonstrates a significant and widespread problem in Northern Ireland given its comparatively small population’.\(^3\) In addition, a research partnership between the Northern Ireland Centre for Trauma and the Transformation and the Psychology Research Institute at the University of Ulster has found that the Troubles have had a distinctive impact on the health of the Northern Ireland population. The study *Trauma Health and Conflict (2008)*

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\(^1\) DSD Benefit Summary of Statistics, Disability Living Allowance, November 2010
\(^2\) Ibid
\(^3\) Centre for Social Justice, *Breakthrough Northern Ireland*, September 2010 pg15
concluded that the Troubles had a significant impact on the mental and physical health of the population and that 12,000 adults had long standing Post Traumatic Stress Disorder with adverse conditions for families and the economy.4

2.3 The Law Centre welcomes the Government’s commitment ‘to supporting disabled people to exercise choice and control and lead independent lives’. We welcome, in principle, the intention to develop personalised support delivered through the PIP; however, given many of the proposals, we are doubtful as to whether this policy intention can be carried through in practice.

2.4 The Law Centre is concerned about the impact, timing and intention of the proposed changes to DLA given the high number of people in receipt of DLA in Northern Ireland. The Department for Social Development has estimated that the proposed changes to DLA will result in a 20 percent reduction in working age claimants once the proposals have been fully implemented. A recent report by the Institute for Fiscal Studies found that, after London, Northern Ireland will be the hardest hit by tax and benefit cuts announced and to be implemented between January 2011 and April 2014/15.5 Northern Ireland will be particularly badly hit because of the high proportion of people relying on Disability Living Allowance and families who will see a reduction in benefit.

3. Areas of concern

3.1 Two rates of PIP
3.1.1 We are concerned by the proposal to remove one rate of the ‘care’ component and support the retention of the three rates of care which allows for greater personalisation of the benefit.

3.2 Six month qualifying period
3.2.1 Upon introduction, DLA, was intended to provide ‘help quickly and effectively’.6 We do not agree with the extension of the qualifying condition period to six months as the new benefit will effectively only be available to those with a long term health condition, expected to last at least 12 months. Claimants suffering from conditions that fluctuate over time could effectively be excluded from receiving help with costs associated with their condition. Many people facing illness or disability, especially when diagnosed suddenly, face significant additional costs as a result. We support the retention of a three month period as any increase in the qualifying time will contribute to a longer waiting period which may have an adverse financial impact on claimants.

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4 Agenda NI December 2010 / January 2011 Issue 43
3.3 Automatic entitlement
3.3.1 The Law Centre is concerned by the removal of automatic benefit entitlement for certain groups. We are concerned that a large number of disabled people will be erroneously subject to assessment due to the narrow entitlement category. We welcome the applicability of special rules for those who are terminally ill. However, the existing categories, for example, deafness and blindness and the severely mentally impaired, should be retained in recognition of the broad effect of these disabilities.

3.4 Older people
3.4.1 We recognise the rationale for increasing the upper age limit of PIP in line with the State pension age. However, given the incentive to reduce expenditure by 20 percent we remain concerned. In Northern Ireland currently, 113,315 over 50s receive DLA while 54,717 over 65s are in receipt. 

4. Assessment
4.1 The Law Centre is concerned by the shift from the social to the medical model of assessment. In particular, the introduction of an assessment, seemingly comparable to the Work Capability Assessment of Employment and Support Allowance does not reflect the social model. Moreover, these changes are being proposed when the Harrington Report recommendations have yet to be fully implemented and evaluated. We welcome the intention to personalise support, however, given many of the proposals, we are unsure as to whether this policy intention can be carried through in practice. The introduction of person-centered, focused assessments, sensitive to the needs of individuals, and the inclusion of evidence from health familiar professionals familiar with the claimant would be more suitable for those with disabilities.

4.2 Fluctuating conditions reveal difficulties caused by exertion, exhaustion and repetition of tasks and reflect the broader spectrum of disability. We believe that ‘information from healthcare and other professionals who work with and support the individual such as their GP or social worker’ should be considered as a matter of course as these are the people most in contact with claimants, familiar with the individuals situation and have a holistic understanding of the condition as opposed to a Health Care Professionals (HCP). Therefore, it is vital that HCP have a good understanding of the particular difficulties individuals may face and the impact this may have on their health and mobility. We recommend that the Government closely consults with organisations representing those with fluctuating conditions, for example, Northern Ireland ME Association and Action MS.

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7 DSD Benefit Summary of Statistics, Disability Living Allowance, November 2010
4.3 We also recommend the enhanced training of frontline staff conducting the assessment. For example, at present we are concerned about HCP conducting the Work Capacity Assessment of the Employment and Support Allowance. The Citizen’s Advice Report ‘Not Working’ has provided quantitative research whereby claimants have reported ‘hurried medicals in which the HCP does not look at them but at the computer screen’. Similarly, Citizen’s Advice (NI) has highlighted delays in processing claims which cause financial hardship for clients.\(^8\) Delays are often caused by the loss of documentation supporting a claim or a lack of communication of follow up from the Social Security Agency.

5. Conclusion

5.1 Welfare reform needs to take account of specific Northern Ireland circumstances. The Law Centre encourages the Committee to highlight the different circumstances in Northern Ireland particularly the significantly greater incidence of mental health problems and the objective ramifications of the proposals to replace DLA with PIP for claimants here.

5.2 Law Centre welcomes the opportunity to provide evidence to the Committee. We trust you will find our comments helpful. If there is any further way in which we could contribute to this process we would welcome the opportunity to do so.

September 2011

\(^8\) CAB (NI) Evidence Briefing available at http://www.citizensadvice.co.uk/en/publications/Social-Policy-Reports/ESA-Evidence-Briefing/
1 The ABI is the voice of insurance, representing the general insurance, investment and long-term savings industry. It was formed in 1985 to represent the whole of the industry and today has over 300 members, accounting for some 90% of premiums in the UK.

2 Executive Summary

2.1 The ABI supports the Government’s decision to review the Disability Living Allowance (DLA) and agrees with the proposed Personal Independence Payment (PIP) and the aims of simplification and personalisation in the welfare system.

2.2 We support the continuation of a universal benefit to help people with the costs of disability.

2.3 Any solution will have to include both support from the state and private provision.

2.4 We strongly believe that the Government should encourage people to consider their protection needs and whether they would have adequate financial support if they become disabled. We also encourage Government to clearly and simply communicate the amount of State support available and signpost people to information about other forms of support available to supplement State provision (such as private insurance).

3 Vocational Rehabilitation

3.1 Occupational health and vocational rehabilitation can help reduce the incidence and duration of disability that requires State support. Employers should be incentivised to invest in the health and wellbeing of their workforce and tax disincentives should be removed.

3.2 There needs to be consistency across Government initiatives. The Public Health Responsibility Deal commitments on health and work could be supported by greater investment in occupational health and vocational rehabilitation. The DWP Sickness Absence Review is considering how to incentivise employers and recommendations will provide useful learning and insight for the Welfare Reform Bill.

3.3 Government’s tax treatment should align with Government policy. The tax disincentive on vocational rehabilitation for employees injured outside of the workplace is a deterrent to employer and employee investment because the tax incurred increases the cost. The employee may opt to wait for NHS treatment, rather than have private rehabilitation that they pay tax on, and by doing so not benefit from early interventions that can get them fit for work sooner.
3.4 The tax treatment is inconsistent because if an employee is injured at the weekend playing sport the vocational rehabilitation is treated as a taxable benefit in kind but if the employee is injured at work the vocational rehabilitation is not taxable. Even though the outcome is the same, that is, the employee cannot work or fulfil their duties effectively.

4 State and private insurance

4.1 There are various funding streams available to people with disabilities. Because DLA (and PIP) is a universal benefit, if someone has insurance covering them for a disability, that person may receive support from more than one source. We regard this positively and do not consider it to be a funding overlap as support from each source can, and sometimes must, be used for different purposes such as replacing income or purchasing mobility equipment. We are interested in exploring how the funding streams from the State and private insurance may be better coordinated and made compatible to maximise the benefit to the person receiving them.

4.2 In particular, we would be interested in discussing how the disability assessment for disability-related insurance claims and the PIP may be better aligned to achieve cross-sector recognition and reduce duplication. For instance, standardising terminology may lead to a uniform system that is more accessible to the public.

5 Communicating the reforms

5.1 The Government needs to improve consumer awareness of the implication of benefit change at both individual and household level, as well as the need for personal responsibility and protection provision should they lack the financial resources to self insure.

5.2 For instance, when communicating reform proposals, we would encourage Government to highlight the absolute minimum and maximum amounts available to people if accessing the PIP – this information will help the public make decisions when planning for future protection needs, particularly when deciding whether private insurance is needed to supplement State support.

5.3 We would also be interested in exploring with DWP how the availability of insurance may be signposted to the public to help with the decision-making process.
Written evidence submitted by the National AIDS Trust (NAT) (PIP 31)

Summary
NAT is the UK’s HIV policy charity. We provide fresh thinking, expertise and practical resources. We champion the rights of people living with HIV and campaign for change.

In our submission, we provide evidence and make recommendations on the following areas of the Committee’s terms of reference:

The implications of a reduction in expenditure
Lower rates of DLA currently have a preventive benefit, helping people with HIV stay well and manage a challenging treatment regime. NAT is concerned by proposals to exclusively focus PIP on those with ‘greatest needs’, as this suggests people with HIV with lower level needs will no longer have the resources to maintain their health. This will make them more likely to develop greater health-related needs in future.

The implications of a six month qualifying period
More than half of people with an HIV diagnosis are diagnosed late, when they will already experience health problems and need to start treatment. Extending the qualifying period will leave them without support when they need it most.

The design of the PIP assessment
NAT does not consider the proposed functional assessment a more accurate method for identifying disability-related needs than the existing DLA assessment. The draft PIP assessment encourages a focus on severity of physical and mental impairment, rather than individual needs and disability-related costs. We are also concerned by the loss of the well-understood concept of ‘supervision’ needs, considered in the DLA assessment.

NAT welcomes the Committee’s interest in the specific issues PIP may raise for people with fluctuating conditions like HIV. We are concerned that the assessment is following the same approach to fluctuation as the WCA, which was strongly criticised by the Harrington review.

The delivery of the PIP assessment
The Harrington Review highlighted a range of problems with the implementation of the WCA, and the most intractable of these were those areas under the responsibility of the private firm contracted to carry out the assessments. The use of a private firm in the delivery of the PIP assessment will likewise lead to less flexibility and transparency in implementation.

NAT recommends the Committee seek a Government commitment that there will be regular independent reviews of the implementation of the PIP assessment, as there has been for the WCA.
The implications of a reduction in expenditure

1. NAT is extremely concerned that the reform process is being driven by a pre-determined 20% budget cut. This undermines the principle that is fundamental to Disability Living Allowance (DLA) - it should be paid whenever a disabled person faces a significant barrier to participation which could be overcome with some help with extra costs. Whereas DLA was developed following a full analysis of the drivers of exclusion among disabled people, there is widespread concern Personal Independence Payment (PIP) development is driven a desire to cut the current caseload and expenditure.

2. The decision to focus PIP on those with ‘greatest needs’ is also a move away from the principles of DLA. The May 2011 technical note to the draft PIP criteria claims that DLA gives “priority to individuals with the greatest needs [in relation to care and mobility]”. This is not the case. DLA recognises that there is a wide range of need amongst disabled people and provides levels of support which reflect this, something that PIP will fail to do.

3. Figure 1 (below) illustrates how DLA currently assists claimants with needs that are quantitatively and qualitatively different. A, B and C all have disability-related support needs around social participation (which can be defined as doing the things they want to do, including work, social activities, civic participation, etc). B is the furthest away from participation, indicating the greatest level of need. A has comparatively much less need than B. However, A is still below the line and needs help to reach it. Under DLA, A might be claiming the lowest rate of the care component, whereas B might be claiming high rates of both care and mobility.

4. If, under PIP, only those with the ‘greatest needs’ are eligible (represented by the dotted line), A would not longer recieve this support. A is still disabled, and still is unable to participate as a result of this disability, but will not able to access the comparatively small amount of support which would make this possible.

5. For people living with HIV, low rate DLA can have an important preventive and health-promoting affect, which could be lost if the current three rates of DLA care component are replaced with only two rates of the daily living component of PIP.
6. For example, DLA can help someone with HIV manage a treatment regime which is both physically and mentally demanding, especially if they experience common HIV-related symptoms such as depression, fatigue and gastro-intestinal problems.\(^1\) DLA may help them access formal counselling, pay for travel to an informal peer-to-peer support group, or simply keep them in touch with an individual support network. Without such preventive support an individual may fail to manage their condition, deteriorate physically and/or mentally, meaning they will require much more costly assistance in future. Spending £19.55 a week to support these preventive measures is a cost effective use of limited funds.

**Recommendations**

**The same range of disabled individuals currently assisted by DLA should also be supported by PIP.**

The committee should ask the Government:
- What evidence it is gathering about the needs of disabled people.
- How many current DLA recipients will not qualify for PIP.
- How the participation-related costs of disabled people who will not qualify for PIP will be met.

**The implications of a six month qualifying period**

7. More than half of new HIV diagnoses in 2009 were people diagnosed late – that is, after the point at which they needed to have started treatment.\(^2\) Even though they may be newly diagnosed when they apply for DLA, their health may be already seriously compromised. They may also be experiencing side-effects of their medication or need support to adjust to a strict treatment regime. At present, this group will have to wait for three months before they can get the help they need to manage their condition and stay well. To extend this to six months will leave people living with HIV without support at the time when they are most vulnerable.

8. NAT does not consider the reasons provided by the Government for this increase are sufficient to justify it. The first reason given for the increase is that it will bring the qualifying period and prospective test in line with the Equality Act definition of disability, which notes that to be considered long term, a condition:
   - has lasted at least 12 months; or
   - where the total period for which it lasts, from the time of the first onset, is likely to be at least 12 months; or
   - which is likely to last for the rest of the life of the person affected.

   (Clearly the Equality Act definition is more complex than this, as certain conditions including HIV are always considered disabilities from the point of diagnosis, so this test does not apply).

9. Aligning with this definition does not necessarily mean that the PIP qualifying period must be six months, followed by a six month prospective test. It would be equally valid to have a three month qualifying period, followed by a nine month

\(^1\) NAT. *Fluctuating symptoms of HIV*. [www.nat.org.uk](http://www.nat.org.uk)

prospective test. The advantage of this arrangement would be those who are diagnosed with HIV late, at a point when they are already in urgent need of support, will not have to wait as long to access PIP. Accessing support at this vital time is likely to be more cost effective in the long run by helping people manage their treatment and avoid deterioration of their health.

10. The second reason given for increasing the qualifying period is to align it with Attendance Allowance (AA). It would be equally valid to align AA with the current DLA qualifying period, and the Government has provided no evidence on why the six month period is preferable for either or both benefits.

Recommendation

The committee should recommend retaining the 3 month qualification period. If the Government wishes to align with the Equality Act definition of a disability which considers a 12 month period, the prospective test should be extended to 9 months to make up the difference. This is particularly relevant for those disabilities (including HIV) recognised by the Equality Act as conditions where the ‘long term’ test is not appropriate.

The design of the PIP assessment

11. The Government has explained that the PIP assessment will use “proxies for an individual’s ability to participate in everyday life” as an indication of the additional costs that may be faced. NAT agrees with this approach in principle. The existing DLA assessment also takes this approach, asking claimants who attend medical assessments questions such as:

- Do you have any problems with using the toilet?
- Can you prepare a meal for yourself using the cooker?
- Do you need anyone with you when you are out?
- Do you go out socialising?

However, the approach to the proxies in the proposed PIP assessment is much more focused on specific functions. These necessarily make the focus of the assessment the severity of impairment.

12. Instead of capturing relevant evidence about difficulties the claimant may have with, for example, using a toilet, and the likely impact of this on their independence and participation, the assessment considers five specific physical functions:

- A. Can manage toilet needs or incontinence unaided.
- B. Can manage toilet needs or incontinence only with the use of an aid or appliance.
- C. Can manage toilet needs only with continual assistance.
- D. Can manage incontinence of either bladder or bowel only with continual assistance.
- E. Can manage incontinence of both bladder and bowel only with continual assistance.

As such, the descriptors end up being a proxy for level of impairment, rather than a meaningful measure of barriers to participation or an indication of how assistance in the form of PIP could facilitate greater independence and
inclusion. This is not in line with the social model of disability which DWP stated would inform the PIP assessment.

**Scoring of the assessment**

13. Similarly, NAT questions the appropriateness of scoring descriptors differently based on how severely impairment limits the claimant’s ability to carry out an activity. Under the draft assessment a claimant will be given one of four or five possible scores for each descriptor. As such, claimants will essentially be ranked according to their level of impairment. This adds a significant layer of complexity, as compared to the DLA assessment.

14. DWP has not provided any explanation of how this will help identify the support needs of disabled people who have barriers to participation. For example, on the ‘moving around’ descriptor, the claimant who is scored on the level ‘B’ descriptor and the claimant scored on the level ‘F’ descriptor both have barriers to participation and would clearly incur extra costs in addressing these. However, B is ranked such that it would attract potentially significantly fewer points than F.

B: Can move at least 50 metres but not more than 200 metres either unaided or with the use of a manual aid
F: Can move up to 50 metres only with the use of an assisted aid.

15. While it is clearly necessary to have a means of distinguishing between standard and enhanced rates of PIP, based on two levels of likely costs, the current scoring proposal goes beyond this. It seems likely to exclude disabled people with support needs who are not considered to have severe enough challenges. This does not fulfil the DWP’s stated aspiration to “treat people as individuals” in the assessment - rather, claimants are assessed as the sum of their impairments and denied support if they do not meet the threshold of ‘greatest needs’.

16. In addition, consideration of the need for various levels of either ‘assistance’ or ‘prompting’ in each descriptor means that the new ‘daily living’ descriptors are in fact making demonstrated care needs core to eligibility. This is contrary to DWP’s claim that PIP will take a more holistic approach than the current DLA focus on whether someone requires care.

**Activities considered by the assessment**

17. NAT has provided DWP with specific comments on each proposed descriptor. This is reproduced at Appendix A.

18. DWP has stated that PIP should support participation among people with disabilities and long-term conditions. However, there is no consideration of social or leisure activities in the assessment. By contrast, DLA eligibility takes into account whether the claimant faced barriers to social activities, participating in their hobbies and attending places of worship, as a result of their health, and if extra support would increase their participation.

19. The other key omission from the assessment is a consideration of utilities costs. The most-cited use of DLA among people living with HIV is ‘paying bills, e.g.
Utilities are one of the most noticeable additional disability-related costs faced by people living with HIV, who need to ensure they keep their home well-heated, and may also face increased gas and water bills associated with needing to wash clothing and linen more often due to night sweats. However, it is currently not considered in any of the draft descriptors.

Assessing fluctuating conditions

20. NAT is part of the working group invited to provide recommendations on how the WCA could be refined to more accurately assess people with fluctuating conditions, including HIV. As the draft PIP assessment takes a very similar format to the WCA, these recommendations should be taken into account in the development stages.

21. The draft PIP assessment is not yet fit for “accurately capturing the impact of variable and fluctuating conditions and ensuring that an individual’s safety is paramount in all cases”. The proposal is that the assessor will:

- consider whether the descriptor applies for at least 6 out of 12 months in the assessment period; and
- score the descriptor based on the need that applies the majority of the time.

To only focus on difficulties which are faced half the time or more is an imprecise and misleading approach to fluctuation, which will lead to inaccurate assessments of need. This is the same approach taken in the Work Capability Assessment (WCA), which Professor Harrington noted was an inadequate approach to fluctuation.

22. Even if a barrier to participation is experienced only a minority of the time, it can incur significant costs to overcome – indeed, the unpredictability of some symptoms may itself create additional costs. For example, if a claimant is using their DLA to help pay for a carer, it is unlikely that they will have the flexibility to not pay for the carer on the days that they feel well enough to manage alone. For complex conditions like HIV, fluctuating symptoms which are not experienced the majority of the time may still be severe enough to impact on participation as much as more predictable or constant health problems.

23. The technical note indicates that all activities considered by the assessment must be able to be carried out ‘reliably, in a timely fashion, repeatedly, and safely’. However, this wording does not appear on the face of the descriptors that will be used. The experience of the WCA has shown that if this wording is not included directly in the descriptor, it will not be consistently considered in assessment. Implementation of the WCA has also shown the importance of

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3 DBC survey
providing guidance to assessors on what this means – e.g. the ability to safely prepare three meals a day, every day, without assistance.

24. Some descriptors differentiate between whether someone needs ‘continual’ or ‘intermittent’ assistance or prompting in order to carry out the activity. In others, points are only allocated where ‘continual’ assistance or prompting is needed (planning and buying food and drink; preparing food and drink; managing medication and monitoring health conditions; washing, bathing and grooming; managing toilet needs or incontinence). This automatically excludes claimants with needs in these areas which are severe but not constant.

25. This new terminology has replaced the concept of ‘supervision’ needs currently used in assessing DLA eligibility for both the mobility and care components. Supervision is well understood by advisers and easy to understand for claimants, and can apply to those with fluctuating conditions as well as those with more constant needs. Separating out this concept to make distinctions between the need for ‘assistance’ versus ‘prompting’ on a continual or intermittent basis adds complexity and the possibility for confusion, which may lead to claimants’ needs being overlooked. For example, the assessment now distinguishes between the following needs, which attract different points:

C: Can prepare and cook a simple meal only with continual prompting
D: Can prepare and cook a simple meal only with continual assistance

Under DLA, both activities are examples of where someone else needs to be present “to avoid substantial danger to yourself or others” and therefore illustrate a need for supervision, which will incur costs to provide.

26. DWP have provided no explanation as to why it is helpful to add this layer of complexity. NAT is concerned that the main outcome will be fewer disabled people attracting sufficient points to be found eligible for the benefit.

Recommendations

The Committee should seek further information from the Government on why a functional assessment is considered a more accurate means of identifying disability-related needs than the existing proxies used to assess DLA eligibility.

The PIP assessment should not take a ‘majority of the time’ approach to fluctuation. Instead, the approach to fluctuation should reflect the recommendations of the independent review of the WCA and the working group on fluctuating conditions.

The Committee should recommend retaining the DLA concept of ‘supervision’.
The delivery of the PIP assessment

27. It is also essential that the problems with the implementation of the WCA, highlighted by the Harrington Review, are not repeated with PIP. The most intractable implementation issues highlighted in the review relate to the interaction between DWP and the private company contracted to carry out medical assessments.

28. The experience of the WCA and the Harrington review indicates that when introducing a new assessment, refinements will be necessary. With the WCA, many of these changes were made relatively quickly— for example, better communication between JobCentre Plus staff and claimants and the development of new training to ‘empower’ DWP decision makers. However, there has been less rapid change where action from the contracted provider, Atos, was required. NAT is concerned that if responsibility for PIP assessments is also contracted out to a private firm there will be less flexibility and room for responsiveness if there are issues with implementation.

29. The use of a private firm means there is less transparency in the delivery of the assessments. For example, stakeholders participating in the Harrington Review have had to rely on second-hand reports from claimants in order to understand the role of the LiMA computer system used by Atos in the WCA, as this may only be viewed in an assessment room on Atos premises. In addition, as certain aspects of the contract are considered commercial in-confidence, it is difficult for stakeholders to analyse and provide comments on how the contracted relationship shapes delivery of the assessments.

Recommendations

The Committee should consider the outcomes of the first Harrington review and ask the Government

• What steps have been taken to avoid the problems experienced with implementing the WCA.
• How they will ensure flexibility and transparency in delivery of the PIP assessment, if a private firm is used.

The Committee should seek a commitment from the Government that there will be regular independent reviews of the implementation of the PIP assessment, as there has been for the WCA.

September 2011

Executive summary

1 DLA is a well-developed and universally admired benefit. It is particularly welcomed in the field of mental health promoting financial stability and inclusion for a marginalized group. Any reforms which are prompted primarily by a need for savings would do better to concentrate on refining and improving initial decision-making rather than opting for over simplifying the qualifying criteria or lengthening the qualifying period, which by necessity will then exclude many of those in greatest need.

Introduction

2 In the community of those with long-term health conditions and their advisers DLA is well understood. It is a sophisticated benefit, with a well-established body of caselaw defining and clarifying the qualifying criteria of benefit entitlement set out in legislation. Once awarded it provides a welcome bedrock of financial support for a defined period for some of the most vulnerable requiring social security assistance. It was intended to promote social inclusion, including access to employment for disabled people, reduce employment disparities and in conjunction with this, reduce inequalities in education and training for the disabled. In this, we would argue it has been successful in its present form.

3 Because of this, any reforms ought to be approached with the utmost caution.

4 Any attempt to “simplify” the qualifying criteria, and more importantly the assessment process runs the risk of throwing baby out with bathwater. We have seen the effects of substituting crude, quick assessments in relation to incapacity benefits. Not only has this led to inappropriate decisions being made, with resultant distress to genuinely unwell claimants; it has also brought the independent Tribunals Service to a virtual standstill because of the high volume of contested decisions. This is costly to the public purse, and runs contrary to the aim of social security benefits – to provide assistance to the unwell in time of need.

Specifics

Qualifying Criteria:

5 The notion of DLA being reformed to focus on those with “the highest needs” in relation to mental health clients is dangerous. Already with the economic downturn we have local authorities and NHS community health services forced to restrict their services to those with critical and substantial needs. As a result of this many mental health service users will shortly find themselves cut adrift from day centre and community support services on which they rely to engage with the wider community. Agoraphobia, social phobia and chronic anxiety are common amongst those with long-term and enduring mental health conditions. Abolishing the Lower Rate Care Component would seriously disenfranchise a substantial cohort of mental health clients who require support to maintain any quality of life in the community. It should not be the intention of social security benefits to only support those with the most florid conditions. That is the role of the NHS.

6 The proposed PIPS criteria appear to focus on the medical model of disability, ignoring the social model of disability. There appears to be an over-reliance on functionality, and a simple conceptualisation of that, which excludes appropriate measures of the impact mental health conditions have on everyday life in the community. We see no evidence of criteria designed to capture
the frequent encouragement and coaxing mental health clients need to get out of bed and engage appropriately in all necessary activities of daily living (i.e. avoid self-neglect). This appears to have been reduced to “intermittent prompting”. Moreover the need for “someone to keep an eye on you” i.e. the supervision requirement seems to have been completely dropped. “Continual supervision throughout the day in order to avoid substantial danger to yourself or other people” is a crucial qualifying criterion for the current DLA. It allows clients who may be at risk because of their symptoms to remain in the community with a network of informal and professional support rather than require admission to institutional support, at far greater expense.

Assessment Process:
7 Advisers have serious misgivings about the assessment process for incapacity benefits. A move towards a similar scheme for DLA with reliance on one off appointments with generalist health professionals with no reference to detailed assessments conducted by specialists who know the applicant intimately is doomed to result in an unsophisticated and ultimately inaccurate appraisal of actual needs. In relation to mental health clients this worry is particularly acute. My team have more than a decade of experience working within what is now a mental health NHS Foundation Trust and in that time we have seen a concerning “dumbing down” of assessments for benefit entitlement for those suffering mental health conditions. Assessments of the symptoms and consequent attention and supervision needs of those with various mental health diagnoses (including the risk factor to self and others) is central to work within the NHS. This needs to be accessed and used constructively by those making judgments about benefits, not ignored or sidelined.

8 We would argue that the current assessment process for DLA entitlement ought to be built upon and improved, not replaced.

9 We need to keep the current self-assessment questionnaire. This provides an opportunity for an applicant, often with help from someone who knows them well, not necessarily a professional, to express the impact of their condition on their daily life.

10 We need to keep the Factual Report, which is commonly sent to the medical professional who knows the client best to give their professional judgment on the applicant’s current abilities/difficulties. We suggest that a significant amount of savings could be made by using more input from HCPs involved in an individual’s care in order to reach an accurate and appropriate decision in the first instance. This is in preference to approaching GPs who charge for a report and lack the specialist knowledge of Care coordinators within Community Mental Health Teams.

11 We need to provide the opportunity for the applicant to send any relevant medical/psychiatric reports which are evidence for the decision to be made.

12 We do not need an additional one off assessment meeting with a DWP appointed health professional. This is expensive and in most cases, in relation to mental health applicants does not add to the sum of available knowledge about the applicant.

Decision-Making:
13 We need to improve and enhance the decision making skills of those currently employed in the Disability Benefit Centres making initial decisions on claims. Currently we are seeing a tidal wave of poor decisions in relation to our mental health clients, completely side-lining the evidence put before them. Again this is expensive for the public purse resulting in initial negative decisions, requiring time spent on reconsideration decisions and in many cases applications to Appeal Tribunals.

14 We suggest that a significant amount of savings could be made by more accurate decision making, which involves more input from HCPs involved in the individual’s care. Guidance given and used by the DMs seems to be actually misleading the DMs as to who is the most appropriate HCP to provide Factual Reports. In short, more effort needs to be allocated to the decision making process, not reducing the amount of the allowance.
Qualifying Period:
15 We have some problems with a six month lead in period for an award as clients experiencing a first episode e.g. of psychosis could be denied access to this benefit at their time of most acute need. Families including children, carers including young carers will also be placed in financial hardship when they need the support the most.

Award Period:
16 Indefinite awards are sensible in the mental health scenario for those with the most enduring conditions. It seems a false economy not to provide these where conditions are not subject to change. To introduce cuts here not only seems a waste of time and resources, it seems unreasonable to subject people to repeated and unnecessary medical assessments which will result in stress, anxiety and possible crisis. We need to provide support for the mentally ill with enduring conditions to keep them in the community if we can, otherwise they would be in a psychiatric hospital with no quality of life, and at great expense to the public purse.

Gateway issues:
17 PIPs should retain the present DLA passporting arrangements. Where our mental health clients are concerned this is of irreplaceable value for Carers (as the entry to Carers Allowance), special consideration within HB regulations, including non-dependent deductions, and housing policies, such as access to self-contained accommodation for younger people. Additionally for those able to take on some work or study, the access to HB for disabled students and access to the disability element in Working Tax Credits is very valuable to independence and the ability to be self-reliant. We would argue that the entitlement to DLA mobility in residential care ought to be reinstated. If removed this will lead directly to social exclusion for an already needy group.

Communication with the public:
18 Training needs to be made available to GPs and NHS staff and disability organisations that assist claimants. Funding for sources of welfare rights advice and representation needs to be promoted and ring-fenced.

September 2011
Written evidence submitted by the Local Government Association Social Security Advisers Group (PIP 33)

This evidence has been drafted and submitted by Local Government Association (LGA) Social Security Advisers Group. The LGA Advisers Group is made up of a range of specialist staff working in local authorities (unitary, metropolitan, district, borough and shire councils), with considerable experience and knowledge relating to benefits and Tax Credits and their interaction with social care services and related issues.

Summary

We have serious concerns regarding the potential reduction in the amount of people who may qualify for PiP. In particular having only two levels of entitlement for daily living. This will reduce the amount of support available for those with lower level needs who may also receive a range of social services. It will have a profoundly negative effect on the lives of disabled people, their carers and families. Disability Living Allowance (DLA) currently provides additional funds to support some disability costs; it also enables them to access other forms of help and helps to provide greater choices and opportunities enabling them to live as normal life as possible, thus promoting social inclusion, without the necessity to interact with social care services.

It suggests the removal of large numbers of people from PiP and appears to have been designed to ensure the reduction in the claimant count and not necessarily seeking to support vulnerable people. The underlying policy appears to be a contradiction of the fundamental principles of social care to promote choice and independence and doesn’t replicate or acknowledge the preventative nature of DLA.

In the absence of any substantive comments from the Dilnot Report relating to the alignment of benefits and social care, the preventative nature of DLA (and Attendance Allowance - AA) must be appreciated and not seen as a form of support only for the most severely disabled and those accessing social care.

We have serious concerns around the potential impact on claimants, their families and carers, local authorities, the advice sector and staff supporting those affected. In particular, those who may experience ‘multiple impacts’ as a result of two reassessment processes, each applying significantly narrower rules than their predecessor.

We are extremely concerned that the reassessment of large numbers of DLA claimants will lead to pressure on front-line social care and health staff across

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1 A 20% reduction in the claimant count was announced in the June 2010 budget
local government at a time of severe economic restraint and pressure on services and additional funding for advice services.

1. 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.

1.1 It is vital that the preventative effect DLA can have on residents is recognised. Many residents who have disabilities are encouraged to claim DLA which enables them to purchase small amounts of care/support that prevent the need for more intensive support. This is particularly pertinent to those who clearly have some level of care, but do not necessarily meet the much higher criteria applied by local authorities. 

1.2 The initial DWP consultation document suggests that DLA spending is “out of control” and is being paid to people for whom it was not intended. However, DWP own research suggests that DLA is significantly under claimed while DLA introduction coincided with the expansion of community care alongside considerable changes in social attitudes to integration and aspirations for people living with disability, so initial expectations of likely claimant numbers were potentially underestimated.

1.3 Local authorities have designed strategies to tackle poverty to ensure vulnerable residents are encouraged to claim their full benefit entitlement. Indeed some of these are statutory duties intended to promote economic wellbeing across all age groups, and to provide benefits advice. Therefore, many processes and policies have been adopted to embed this into everyday practice. Local authorities have also worked tirelessly through their health and social care partnerships to ensure DLA is better understood both by claimants, practitioners and professionals. By actively promoting the benefit across a range of services and potential claimants, barriers and the stigma around claiming have reduced. We suggest that some increases in the take up of DLA show that its purpose is better understood by a wider range of claimants and has lead to increased rates of take up.

1.4 Local authorities have continuously worked closely with colleagues in health and housing and community organisations, to tackle problems around low levels of take up. This has also included working with DWP to secure improvements to the claim form and decision makers’ awareness of where to gather appropriate supporting evidence.

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2 FACS - Fair Access to Care Services. Most local authorities only provide services to those with critical and substantive needs
3 Local Government Act 2000
4 Fairer Charging
1.5 Another important factor in the increase of the caseload may be attributed to an aging population, many of whom may not necessarily enjoying good health and mobility in latter years. In addition, considerable advances in neo/ante natal and medical technology will have given rise to ‘miracle babies’ who despite surviving through the most complex of conditions and complications may be left with lasting care and mobility needs.

1.6 The DWP has also responded to research around the barriers to claiming DLA to help ensure the benefit is correctly focused. For example The Social Security and Mental Health Report\(^5\) identified areas of improvement that would ensure better reach of DLA. Their recommendations helped improvement the claim pack to address the needs of people with mental health conditions, and also improved areas of poor decision making, particularly those with multiple conditions. We would therefore submit that the purpose of DLA is no longer as misunderstood, nor does it fail to target those in greatest need, and improved communications around the nature and reach of the benefit would continue to ensure its take up.

2. 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.

2.1 In the absence of the scoring of the draft descriptors and the pilot exercise, it is difficult to quantify and assess the real impact on social care users and social care departments. However, we are convinced that only having two daily living components will potentially exclude considerable numbers of people who have more moderate needs/conditions, but who also have legitimate care needs i.e. those who have learning disabilities, people recovering from stroke.

2.2 Figures available from DWP\(^6\) show that across the UK, of the 3,220,360 claimants entitled, 900,080 of them were in receipt of the lower rate care component. (See embedded object below). With the introduction of PIP these claimants would potentially lose their entitlement which is seriously concerning. Not only in terms of the loss of income to the claimant, their families and carers, but the possible demand for services and support. Whilst below we note that there is no data available on the overlap of claimants and social care users, it is likely that a high proportion of them would be receiving some support from social care and that users would seek to have these needs met. In addition, as detailed below, the lack of distinction between day and night needs in PIP will pose a considerable issue for local authorities when it comes to charging for care.

\(^5\) M Hirst and Roy Sainsbury
\(^6\) [http://83.244.183.180/100pc/dla_ent/careawd/ccgor/a_carate_r_careawd_c_ccgor_feb11.html](http://83.244.183.180/100pc/dla_ent/careawd/ccgor/a_carate_r_careawd_c_ccgor_feb11.html)
3. The extent to which overlaps in funding exist, particularly with local authority and NHS funding, and including for people in residential care or hospital.

3.1 DLA has become an increasingly vital means to promote independence, and as such is a key stream of funding for innovative supported living schemes and an integral feature of the personalisation agenda for social care. There is no available data on the overlap of social care users and DLA recipients, but it fair to state that whilst not all DLA recipients receive social care services, a considerable number do and is a key consideration as part of their care options/plans. It is also a key feature for the local authority in the charging and funding of care packages.

3.2 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. The necessary data to examine the extent of this would require each local authority to extract that information from their various systems and as such is something they may wish to do to attempt some assessment of the likely loss to their authority. This also may be necessary given there appears to be no distinction in PiP between day or night-time needs in the awards and the distinction is clear with regards fairer charging policies. The lack of distinction could present considerable issues for local authorities to ensure they operate their policies legally. Whilst the full extent of this needs to be examined, improved information sharing between local authorities and DWP might be part of the solution.

3.3 We are aware that the recent Dilnot report did not provide any in depth discussion/recommendation in terms of DLA and social care. It did however state that there needed to be some alignment. However, the Dilnot report did not address or acknowledge the preventative effect that both DLA and AA can have in supporting people to live independently. It is therefore vital that PiP is not seen as a form of financial support only for those accessing care services.

3.4 We are mindful of the current call for evidence from the Low Review into the mobility funding of people in residential care. We will await the outcome of that review before passing further comment. However, it must be noted that it is an extremely important form of funding for those in residential care (including young people in residential settings and those in temporary care); if removed would place an additional burden on local authorities. We would suggest both rates of PiP mobility would need to be paid to continue to provide this vital form of funding for disabled people in meeting the cost of their mobility needs regardless of the rate and setting in which they live.

3.5 With regards access to Motability vehicles, exemption from vehicle excise duty, automatic entitlement to Blue Badges etc, subject to discussions around the
scoring that we have raised above, PiP Mobility needs to replicate the same forms of help.

4. Implications of a six month qualifying period

4.1 We have concerns with the proposal to increase the qualifying period from three to six months. The sudden onset/deterioration of a condition can often adversely impact many areas of a person’s life, and additional financial support at an earlier stage could prevent or delay any exacerbation of their difficulties. Early intervention has been a foundation of the support and policy for the introduction of Employment and Support Allowance. We believe that the current “forward test” sufficiently ensures that only those with longer term conditions are entitled and the extension would place unnecessary burdens those affected including carers. In addition, these people are still as likely to look to local authorities for support (including financial support) placing additional costs and burdens on stretched local authorities. This burden may also result in less income from charging for care, adding further burdens on local authorities.

5. The extent to which PiP will act as a gateway to other benefits, including Carers Allowance and the Motability Scheme.

5.1 Currently entitlement to Carers Allowance is reliant on the disabled person/child being in receipt of the middle or high rate of care component. Given the two levels of daily living need and awards i.e. standard and enhanced, it is not clear how Carers Allowance will align to both of the daily living components. In the absence of any data on how many who currently receive middle or high rate care will pass the new eligibility criteria because the scoring is still undetermined, how many carers will be affected is also unknown. However, it is important to note the vital role carers play in maintaining the independence and providing care for disabled people and children that would otherwise need to be met by local authorities. Also given the large numbers of carers in the UK and the savings they are said to save the economy (including dwindling local authority resources) we would suggest that the link is made via the standard award of PiP as opposed to the enhanced award.

5.2 As shown in the examples, the loss of DLA can have a devastating impact on the incomes of carers and their families, and many carers could feel forced to look for work and may not be able to continue to provide care. They may then look to support from local authorities who may not necessarily have the essential resources to meet additional demand whether directly or through partners who may also be experiencing cuts to resources.

7 According to figures published by Carers UK approximately 6,000,000 carers in UK save the economy £119 billion per year [http://www.carersuk.org/professionals/resources/quick-statistics](http://www.carersuk.org/professionals/resources/quick-statistics)
6. The design and delivery 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. 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.

6.1 The introduction of a detailed list of descriptors seems to make eligibility more complex. The new descriptors are still open to interpretation, such as ‘continual prompting’ and ‘continual assistance’, therefore complexity and the potential for confusion remains.

6.2 The current assessment is primarily based on a lengthy claim form, backed up by medical or social care evidence on occasions, and subject to further assessment by a DWP-contracted examining medical practitioner (EMP).

6.3 It is important to retain principles of self assessment and a social model of disability, backed up with reports from involved and suitably qualified health and social care professionals, rather than to extend the role of medical assessments, which have always proved problematic in determining benefit entitlement.

6.4 Snap-shot opinions from a clinical viewpoint, not informed by full knowledge of the disability or even medical history, are often at the heart of poor decision making. The decision to introduce DLA and replace Attendance Allowance was taken because of acknowledgement of the failure of snap shot medicalised assessments, and the problems caused by over reliance on medical assessment was also highlighted in the Harrington review.

6.5 Government states that there is no systematic way of regularly checking that an award remains correct although this appears at odds with claimant and adviser experience given DLA claims are subject to regular and periodic reviews and reassessments. DWP own research into levels of payment error suggest there have been improved in accuracy levels of DLA. This has been achieved through improved training and improved knowledge of decision makers. Further improvements to decision making could be achieved by continuing this direction and bringing in further training with consideration of the need for specialist claim assessors for mental health, learning disabilities and children’s claims rather than bringing in an the EMP-led ESA assessment. Currently of the unsuccessful decision relating to ESA that are appealed 39% succeed.

6.6 The proposals will place much greater emphasis on a mandatory EMP report. These will be similar in style (but not content) to the controversial assessments being carried out on ESA claimants that has led to considerably higher refusal
rates than originally anticipated. All of this places undue burdens on claimants, their family and carers and staff supporting them and includes the increased administration of HM Courts Service dealing with appeals.

6.7 Further consideration should be given regarding the sharing of assessment information between the DWP and health/social care staff removing the need for medical assessments.

6.8 It has been stated that DLA awards can be inconsistent and unfair. Whilst the quality and accuracy of decision-making on DLA is not universally good it is not clear how the new test would not improve this. The LGA is aware of research on who closed working with colleagues in health and social care to share assessments can improve decision making.

6.9 There has been no evidence provided to explain why the new face to face assessment would improve decision making. The assessment procedures appear to replicate the approach of ESA with the introduction of a snapshot medical assessment that has not improved decision making, especially for those with mental health and cognitive functioning and those with fluctuating conditions. This suggests the lessons from Harrington have not been put into practice. However, experience of the EMP-led ESA assessment does not inspire confidence in a more accurate system being in place for PiP. The number of ESA appeals has risen by 56% in the last two quarters and the success rate of those who are represented at appeal remains particularly high as previously mentioned. If the problems identified by the Harrington report with medical assessment of ESA and poor decision making, large numbers of people will lose benefit unfairly because of the more stringent test and poor assessment processes.

6.10 The scale of the migration from DLA to PIP is similar to that for ESA but would appear to be a quicker implementation schedule. Large numbers of people will have to be assessed over a short time. If the process goes wrong, the implications will be far-reaching with little time to put things right, placing additional burdens on the advice sector, front line staff in social care and other staff and advocates supporting those affected. It is also important to bear in mind that these claimants may have already been through one reassessment process. Claimants may feel unduly stressed and unsettled and upset by the experience and may even experience deterioration in their condition, thus requiring additional support from local authorities and/or advice agencies, at a time when funding and resources mean less support is available. In particular local authorities have had to reduce funding to many of their partners, resulting in delays and less support staff/volunteers being available.

6.11 Whilst appeals are possible, these are time consuming and are an additional burden on the claimant and their carers and representatives, in particular those who support vulnerable claimants including staff in local
authorities. Given the timescales involved in the appeals procedure, the loss of income and other support to the claimant, their family and the resource implications for local authority, it is vital that the piloting and assessment of the changes are not rushed. Examples of how this could impact on individual cases can be found at Appendix A.

6.12 This loss of income to meet disability costs will lead to greater demand on care and support services, as the preventative nature of DLA is removed but also through loss of passported benefits and interaction with other benefits including Housing Benefit. This would put extra pressure on already hard-pressed services and the individuals concerned would have less income available to meet the charges that accompany those support services. The proposals, if unamended, could lead to greater poverty and a resultant breakdown of health and social functioning – the link between poverty and ill-health is well-recognised and the link between poverty and mental ill-health in particular is of significant concern.
Appendix A

Case studies

Case Study 1 – the Benefits Cap and the new Personal Independence Payment

Before
- Sid and Amanda live with their 3 children.
- Amanda provides care in the home.
- Sid has brain injuries from a road traffic accident which affect his behaviour and can make him aggressive, he has problems with planning and sequencing processes.
- The family pays £300 rent pw for their 3 bed house.
- As well as £300 pw in Housing Benefit, the family also claims £390.56 in other benefits which includes ESA for Sid, child benefit, child tax credit, carers’ allowance for Amanda and the middle rate of DLA (care) and high rate DLA (mobility) for Sid.
- The fact that Sid receives DLA means that the £500 pw benefits cap does not apply to the household.

After
- While being migrated from DLA to the new Personal Independence Payment, Sid is reassessed using the more stringent assessment process and told that his disabilities are not sufficient to merit an award of PIP. He does share information clearly with the medical examiner as he lacks insight into the severity of his condition.
- This decision means the family lose Sid’s £ DLA middle rate care component and low rate mobility component.
- It also means they now are subject to the £500 pw benefits cap.
- After paying their £300 pw rent, they now only have £200 pw to meet all their living costs where previously they had £390 pw.
- They have a £190 per week shortfall in income which will cause severe hardship.
- The family may well have to move to smaller accommodation to manage financially.
- His wife is no longer able to receive carers’ allowance.
Case Study 2 – Shared Accommodation Rate

Before
- Jim is 31 and has autism.
- He is informally supported by friends/family who live in the area so does not access council-funded services.
- He rents a 1-bed private rented sector flat which costs £150 pw – this is paid by HB.
- He also claims ESA.

After
- Jim is reassessed and assessed as no longer being entitled to DLA.
- He is now subject to the Shared room rate as he is under 35.
- He is told he now only qualifies for the Shared Accommodation Rate of £85 pw.
- He has an instant shortfall on his rent of £65 pw which he cannot possibly make up from his personal income.
- Jim is told he cannot afford to rent a two bed in Lambeth with another adult sharer as the £85 pw Shared Accommodation Rate he has available to spend is not enough to cover his half of the rent (£100 minimum).
- Jim has to move to a cheaper area – away from friends/family – or share a larger property. He chooses the latter option but experiences difficulties with his housemates and suffers bullying due to his autism. He becomes depressed.
The Scottish Disability Equality Forum (SDEF) works for social inclusion in Scotland through the removal of barriers and the promotion of equal access for people affected by disability.

We are a membership organisation, representing individuals with any type of impairment, disability organisations and groups who share our values. It aims to ensure that the voices of people affected by disability are heard and heeded. SDEF promotes access in its widest sense, including access to the built and natural environment and access to the same opportunities as are enjoyed by other people in our community.

This submission considers the impact of the proposals regarding aids and adaptations.

SDEF has undertaken a range of research into the Personal Independence Payment proposals. We received responses from over 50 of our members to an internet survey, including both yes/no questions and freestyle comments. SDEF also held consultation events Edinburgh and Inverness with 60 attendees. These offered a wide range of options for delegates to give their opinions; including workshop discussions, comment sheets and video blogs. The full range of this evidence is included throughout the submission. Direct quotes from our members are given in italics.

**Executive Summary**

**Recommendations:**

1. Using an aid or adaptation to complete a task is not the same as being able to do so unaided. This should be reflected in the assessment.

2. There are a wide range of environmental and personal factors that affect the utility of an aid or adaptation. This highlights why an unsophisticated blanket approach is ineffective.

3. Aids and adaptations come with necessary and unavoidable extra costs. The Personal Independence Payment should be structured to recognise and provide for these costs.

4. The Personal Independence Payment should be designed to incentivise the use of independence boosting aids and adaptations.

1. **Using an aid or adaptation to complete a task is not the same as being able to do so unaided. This should be reflected in the assessment.**
1.1 Our members assert that the proposals risk considering the use of aids and adaptations as a panacea.

1.2 ‘The inference is that a person who successfully uses aids and adaptations can be labelled as not in need of help. No consideration is given to the effort required to use these and the overall effect of having to make this effort.’

1.3 This is extremely important and highlights a significant flaw in the way aids and adaptations are proposed to be considered. The way the descriptors are designed equates being able to complete a task using aids and adaptations with being able to do so unaided. However, this is a far from reasonable comparison.

1.4 ‘The use of aids masks the reality of how limited mobility and care is and hides the internal symptoms of pain, fatigue and stiffness.’

1.5 Our members find this approach does not reflect the values of independent living. It does not acknowledge, or give respect to a disabled person’s experience of life.

1.6 ‘Of course it is taking an aid as a replacement for disability of the human part that has been lost, the pain and mental distress is written off and insults the disabled.’

1.7 This encapsulates the problem. Using an aid does not remove pain. Using an aid requires its own effort and exertion which has an impact on the person making the effort, particularly in relation to fatigue. This cannot simply be calculated using the checklist style descriptors. This is particularly the case for complex and fluctuating conditions. The assertion, implicit in the descriptors, that, for example, being able to walk 200 metres unaided is the same as being able to do so with the use of a manual aid is irrational, unreasonable and unjust.

1.8 ‘Just because you can do something with an aid doesn’t mean that it is as easy to do it as a non-disabled person’

1.9 Aids and adaptations can be of great benefit to disabled people. However useful an assistive device is and however adept a disabled person is at using it does not change certain facts.

1.10 ‘We appear more able when we use our aids and adaptations. But our disability is not reduced by the aids.’

2. There are a wide range of environmental and other factors that affect the utility of an aid or adaptation. This highlights why an unsophisticated blanket approach is ineffective.
2.1 Another aspect that the proposals fail to consider is that various environmental factors can affect the utility of aids and adaptations. As one of our members highlights:

2.2 ‘As a wheelchair user - no consideration has been taken of surface or topography. i.e. I can travel 200m downhill with ease, relatively quickly on a level surface but, dependent on the gradient it would be slower going uphill to impossible if the slope was very steep. This would also be dependent of the surface: - Asphalt, concrete, tarmac - easy Cobbles - slower Grass, gravel - difficult to impossible dependent on weather conditions and how well impacted.’

2.3 Although this example is specific to wheelchairs the general point is applicable across the board. For example, electrically powered devices can be helpful but are completely useless if their power supply is affected. This is out with the control of the person using the device and would leave a disabled person vulnerable, especially faced with a diminished benefit payment to help plan against such events.

2.4 The impact of an impairment or condition can vary significantly depending on where a person lives. This can significantly affect the utility of an aid or adaptation. For example, the availability of accessible transport will impact upon a person’s mobility regardless of whether or not they choose to use any aids or assistive devices. This point was particularly emphasised at our Inverness event and by other members in the more rural or remote areas of Scotland.

2.5 ‘Being able to move around is one thing being able to access is another. I am a wheelchair user, access to 100% of building is extremely rare as obstacles such as steps and furniture set up are not being considered. Wheelchair access is usually the longest distance.’

2.6 This highlights the fact that although a disabled person may be able to move the requisite distance to meet one of the lower descriptors through use of an aid, this apparent ability can be significantly diminished by a range of factors completely out with the control of that individual. SDEF proposes that in developing the categories a design of ‘Access to...’ would be more suitable. This will help to ensure that all aspects are considered.

2.7 In its widest sense ‘access’ means considering the physical, social, economic and other barriers disabled people face in participating in everyday life. If the Personal Independence Payment is designed to consider these barriers in combination, rather than in isolation, then the true impact of an impairment or condition may be reflected.

3. **Aids and adaptations come with necessary and unavoidable extra costs. The Personal Independence Payment should be structured to recognise and provide for these costs.**
3.1 Another important factor is that only the aids and adaptations a person actually uses will be considered. This has lead to criticism of unfairness:

3.2 ‘Aids and adaptations are not what makes me disabled. If someone with the same disability chooses not to use the available aids, or has someone living with them who does the tasks they cannot manage, they become entitled to a higher benefit. I don't grudge anyone a higher benefit, but it is clearly an uneven playing field.’

3.3 Our members note that this unfairness can be influence by other factors in a person’s life. For example the availability of support and assistance from family

3.4 ‘I use a great deal of electrically operated aids eg a lifting/rising toilet. Friends of mine use their relatives to do this instead. Therefore they get 'fulltime care’ and would also receive more in benefits. Also all the electrical equipment needs maintenance when not supplied by social services, and this costs a very great deal of money.’

3.5 Our members strongly believe that the proposed assessment will penalise people who make effective use of aids and adaptations and that the scheme will not ensure individuals get the support they need.

3.6 ‘I have purchased, using DLA, a number of items that enable me to do the sort of tasks to be assessed. If my benefit is reduced because of these aids and adaptations I will be unable to replace them when they expire, as they surely will. I will then have to go back through the assessment process, which is inefficient for all, or face a reduction in my independence.’

3.7 This identifies one of the main flaws in the way aids and adaptations are proposed to be considered. The idea that a person should have autonomy in deciding whether or not to use aids or assistive devices is laudable. However, when a decision not to use such devices can lead to a higher payment, through meeting a higher descriptor, then this will act as a substantial disincentive to use aids and adaptations. These aids can be of significant benefit to enable a person to realise their right to live independently. As the example from our member points out it would be highly inefficient (not to mention painful for the individual) if someone received a reduced benefit due to their use of an aid, only for that aid to break and not be repaired or replaced due to the benefit reduction, for that person to then be reassessed back onto the higher level, to then re-purchase the aid, to then re-lose the benefit. This is a plainly a vicious circle and presumably not the intended effect of the Personal Independence Payment. The system must not be reactive. A preventative approach, aimed at not only achieving but sustaining independence, is essential.

3.8 Aids and adaptations can boost independence but they come with inevitable and unavoidable costs. The current proposals do not recognise these costs, this must be remedied to uphold a disabled person’s right to live independently.
4. The Personal Independence Payment should be designed to incentivise the use of independence boosting aids and adaptations.

4.1 The respondents to our online survey were split as to whether aids and adaptations should be considered, with a small majority (54%) in favour. There were two notable trends of opinion among those who thought aids and adaptations could be considered.

4.2 The smaller group of affirmative respondents thought that aids and adaptations should only be considered as demonstrating the degree of disability with which a person was affected. Requiring an aid to perform certain tasks should be seen as a measure of disability. Therefore, an individual who cannot travel a relatively short distance but for the use of a manual aid should be recognised as requiring the Personal Independence Payment. This can be contrasted to being seen as ‘able to cope’, as implied by the current proposals.

4.3 ‘I don't think aids should be considered, apart from showing that the person is disabled in the first place!’

4.4 However, of those in favour, the majority view was that this aids and adaptations must be considered constructively.

4.5 ‘I think these should be considered in a positive manner, that is, if someone’s life could be improved with the provision of an aid, then they should be enabled to acquire and maintain this. This is a distinct shift from the punitive approach which seems to be advocated to date.’

4.6 This was also emphasised at our consultation events with delegates suggesting that a premium to purchase aids and adaptations could be put aside from the DLA budget to specifically enable this purchase.

4.7 ‘I think the emphasis is on a short cut riddled approach to saving money. As such, anyone who’s seen as making the best of a bad job through using assistive devices becomes a target for cutting support. On the contrary, people must be encouraged to make the best of their lives.’

4.8 If the reforms are targeted at actually improving the lives and boosting the independence of people in receipt of DLA then savings can be made elsewhere. This could be through easing pressures on other budgets, such as health and social care. This would be in accordance with the preventative and personalised approach widely advocated as the best, and most cost effective, approach to public spending for the future.
Survey of SDEF membership:

We asked are members:

- Do you think the sliding scales will mean that someone who uses aids and adaptations will get the level of support they need?
  Yes – 12.5% (5)  No – 87.5% (35)

- Do you think that considering aids and adaptations could penalise disabled people who make effective use of them?
  Yes – 75.6% (31)  No – 24.4% (10)

- Do you think that the aids and adaptations should be considered at all?
  Yes – 53.7% (22)  No – 46.3% (19)
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\(^1\) and to the draft regulations\(^2\). 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.

\(^1\) 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.

\(^2\) The proposed Personal Independence Payment: the draft regulations - key issues for blind and partially sighted people, 9 VI sector organisations, June 2011.
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 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\(^3\).

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

\(^3\) See note 2.
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.

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\(^4\), containing a great deal of further evidence.

5.3 We should be happy to provide further information on request.

\(^4\) See notes 1 and 2.
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.

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 4 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 eleven activities where it is proposed you might automatically score fifteen 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 per cent) 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.
1. Introduction

1.1 The National Deaf Children’s Society (NDCS) is the national charity dedicated to creating a world without barriers for deaf children and young people. We represent the interests and campaign for the rights of all deaf children and young people from birth until they reach independence. There are over 45,000 deaf children in the UK and three more are born every day.

1.2 NDCS offers a range of services to families including a core team of 3 specialist benefits advisors, who supported 335 families in the last year as well as a team of 25 family officers around the UK who provide advice to parents of deaf children on claims, revisions and appeals for Disability Living Allowance (DLA).

2. The need for DLA reform

2.1 NDCS recognises that DLA could be improved through simplification of the benefit and a better understanding of the barriers faced by deaf children and young people and their families. For example, in 2010 NDCS worked with a number of organisations and the Pension Disability and Carers Service (PDCS) to simplify the DLA claim form for children. This has now been successfully tested and we urge that care is taken to ensure that learning from this process is not lost in the current reforms.

2.2 However, we are extremely concerned that the Department for Work and Pensions’ rationale behind proposals to replace DLA with Personal Independence Payment (PIP) is primarily a means of “saving 20% of the Disability Living Allowance in line with the Chancellor’s commitment in the 2010 Emergency Budget” and not truly concerned with improving the benefit.

3. The implications of a reduction in expenditure

3.1 We understand that the Government wishes to focus on those “in the greatest need” and that some of those currently receiving awards will cease to receive financial assistance. NDCS believes that deaf young people will be badly affected by this and that the decision to make savings by cutting assistance to this group is short-sighted, and will result in greater pressure on public finances in the longer term. For example, deaf young people often use DLA to enable them to attend social activities which other young people take for granted. Loss of this support can lead to social isolation and low self esteem and emotional well-being. 40% of deaf young people already experience mental health problems, and loss of financial support will only exacerbate this and create extra pressure on mental health services.

3.2 Targeting only those disabled people with the greatest need will exclude many deaf young people who still face additional costs associated with their disability. The draft assessment criteria and regulations for PIP also suggest that it is likely that

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1 Maria Miller – [http://ablemagazine.co.uk/exclusive-interview-maria-miller-mp-on-the-dla-consultation](http://ablemagazine.co.uk/exclusive-interview-maria-miller-mp-on-the-dla-consultation)
many deaf children who currently receive the middle rate of the care component will not qualify for PIP. It appears that sensory impairment alone will not be sufficient to allow a person to qualify for either the daily living or the mobility component of PIP. It appears that their difficulties with communication or with planning or following a journey will only count if they suffer ‘overwhelming psychological distress’. This is extremely worrying as removal of this support will prevent deaf young people being able to lead full and active lives.

3.3 At present the 3 rates of care component provides the lower rate for those with additional needs for a significant portion of the day. The criteria of the lower rate care are not due to a lower level of need, only a lower frequency of attention needed. With less support available for those currently receiving the lower rate, their condition may deteriorate so that ultimately they qualify for a higher level of DLA.

3.4 A parent of a profoundly deaf child with additional complex needs who currently receives DLA care component at the highest rate and the mobility component at the lower rate, recently told us,

‘It allows me to have the piece of mind in the winter to know I can afford to have the heating and lights on. Toys/equipment is generally more costly as it has the tag "special needs" on it so it allows me to buy toys/equipment to help my son develop to his full potential.’

4. Whether automatic entitlement should apply to people with some conditions or impairments and whether some people should receive awards for indefinite periods.

4.1 NDCS recommends that permanent deaf/blindness should retain an automatic entitlement to the highest rate of the mobility component under PIP as under DLA, as this will ensure the benefit is targeted at those who most need it and will be a more effective use of resources which will not be wasted on unnecessary assessments.

5. The implications of a six month qualifying period.

5.1 The Government has stated that they are planning on increasing the qualification period before adults are entitled to PIP from three months to six months. It is currently unclear what the qualifying period for PIP would be for under 16s.

5.2 NDCS is very concerned about the consequences increasing the qualifying period for DLA/PIP to six months would have on deaf children and their families. This will mean that children born deaf will have to wait until they are six months old before being entitled to DLA/PIP having a detrimental effect on families with deaf children at a crucial early stage in their child’s life. Families with babies who are born deaf face additional costs related to their child’s disability immediately from diagnosis. For example, specialist health appointments that a deaf child has to attend are frequent for younger deaf children as their needs with regard to hearing equipment and other support change very rapidly. Young babies need new ear moulds for
hearing aids as often as every two weeks. The logistics of attending these numerous appointments is a substantial cost that families face straight away.

5.3 The world leading Newborn Hearing Screening Programme now means that the 50 per cent of deaf children who are born deaf are identified shortly after birth. This is a valuable opportunity to start giving deaf babies and their families the support they need right from the start, which will be squandered if they do not have access to financial support. We know that early intervention with deaf babies and children is crucial if they are to acquire language skills and be able to participate fully in society. 6 months is a very long time in a baby’s or small child’s life. We therefore recommend that there be no qualifying period for children under 5 with a diagnosis of deafness that is expected to last for at least 6 months.

6. The extent to which PIP will act as a gateway to other benefits, including Carers Allowance and the Motability Scheme.

6.1 DLA has been very important at getting deaf children and young people and their families access to other services. For families on means tested benefits, entitlement to premiums on their other benefits helps lift them out of poverty. For families with young children or older children with additional needs, passporting to Carer’s Allowance enables the parent to provide the additional support that their child needs at the time they need it rather than having to buy in care from a stranger who is unlikely to be aware of the child’s communication preferences.

7. The design of the PIP assessment

7.1 Assessment criteria and design - Face to face assessments are completely inappropriate for deaf young people under the age of 18, and should not be considered for this group. Face to face assessments for benefit can be very stressful and are likely to harm the self esteem of children and young people. It is unrealistic to expect most children and young people under 18 to present accurate information on the impact of their disability to an unfamiliar professional. We know that 40% of deaf young people will already experience mental health problems. Subjecting this vulnerable group to a stressful assessment process will exacerbate this leading to more pressure on NHS services.

7.2 We know that in assessment situations with professionals, deaf children and young people are often accompanied by a familiar adult who may provide informal communication support. This may include using signs or repeating questions, as an unfamiliar professional may be harder to lip-read. This gives the professional carrying out the assessment an unrealistic view of the child or young person’s ability to communicate in unfamiliar situations with strangers.

7.3 NDCS submitted comments on the draft assessment criteria published by the Department for Work and Pensions where we highlighted concerns that as they stand the criteria will mean that deaf young people are denied the support they need. We are also concerned that the descriptors in this initial draft assessment criteria cover only the most basic functions of life and do not consider supervision that is necessary to ensure the person’s safety. No consideration is given to social or leisure activities. However, we strongly believe that PIP should not just be about
basic survival, but should also enable a person to have a reasonable quality of life. It is unlikely that the government will meet its commitment to provide ‘support to help overcome the barriers which prevent people from participating fully in everyday life’ unless this is addressed in the assessment criteria. Full comments on the initial draft of the assessment criteria are available at http://www.ndcs.org.uk/document.rm?id=6183.

7.4 **Aids and adaptations** - It is a common misconception that an aid or adaptation will enable a deaf young person to completely overcome the barriers they face. Aids and adaptations do not create a completely accessible society and to allow deaf young people to live ordinary lives many of them and their families will still incur additional costs. Hearing aids, cochlear implants and bone anchored hearing aids and other equipment may assist a deaf person in understanding the spoken word but do not give them hearing equal to that of person who has no hearing impairment. Variables such as background noise, busy streets and unfamiliar dialect still lead to confusion.

7.5 We are also concerned that to financially penalise young people and families for having suitable equipment would be extremely damaging. It would reduce their ability to contribute towards aids and adaptations that meet children and young people’s wider wellbeing needs and help them live a more independent and ordinary life.

8. **The delivery of the PIP assessment**

8.1 Given the experience with Employment Support Allowance assessments, we are very concerned about the quality of assessment for PIP and the training and understanding of those tasked with carrying it out. We seek assurances that the assessment will not be a computer-driven ‘tick box’ process, but will take a holistic approach to the person, focusing on the effects of their disability on all aspects of their life.

8.2 A face to face assessment should be only one part of the process and decisions should not be made based on a snapshot of the person at the examination, but must take account of all other reports that have been supplied. The assessor should also be able to recommend that further reports are obtained from the claimant’s own professionals, where this would enable a more accurate assessment to be made. The assessor should have training in the effects of specific disabilities on people’s lives. Where the assessor does not have knowledge of a particular disability, he or she should have access to specialists for further advice. The assessment for PIP should be free standing, focusing on the criteria for PIP alone and should not rely on assessments that have been carried out for other purposes. In the interests of fairness and transparency the person being assessed should be told in advance the descriptors they are being assessed against, the scores given for each descriptor and the scores necessary to qualify for PIP. The decision in all cases should be taken by the decision maker in the DWP, who should make the decision independently from the healthcare professional carrying out the assessment.

9. **How DLA/PIP should apply to children**
9.1 On the face of the Welfare Reform Bill it is not clear how the Government intends to reform DLA for under 16s. This has resulted in debate in the Commons stage of the Bill focusing on the system for working age adults. NDCS is concerned that the lack of debate and the legal implications of the Bill may result in the creation of a new benefit system for deaf and disabled children without proper debate and parliamentary scrutiny. NDCS believes that there is a valid case for the design of PIP to be different for under 18s. In the past DWP has recognised that the system needs to work differently for children and has successfully piloted a specialist children’s claim team.

9.2 These concerns on the lack of clarity on the design of PIP for under 16s were addressed to some extent by the Government’s response to its consultation on DLA reform where it confirmed the intention is to extend PIP under 16s in the future but not in 2013/14. The Government also recognised that under 16s need an assessment specifically designed for them. They also stated that under 16s will not be moved onto PIP without a public consultation and any decisions made will be subject to Parliamentary scrutiny.

9.3 NDCS welcomes the Government’s assurances that there will be some debate and scrutiny of any changes to DLA for under 16s. However, we are concerned about the implications of reform on deaf young people turning 16 after 2013. If children are to be moved on to PIP, we are especially concerned that those currently receiving the lower and middle rates of the care component may find they cannot qualify for PIP. In order to qualify for the middle rate of DLA a child must demonstrate a high level of need, to satisfy the DWP that they need either frequent attention in connection with their bodily functions throughout the day or that they need continual supervision throughout the day in order to prevent substantial danger to themselves or others. In the case of children under 16 their need must be substantially greater than an average child of their age. Many deaf children need help throughout the day with communication. However, with the very restrictive definition of communication support in the draft regulations, it seems likely that very many of these will be unable to qualify for PIP. Deaf babies and very young children with hearing aids and cochlear implants require a very high level of supervision because the aids are choking hazards and the batteries are toxic. There is no reference in the draft regulations to supervision needs. We are unable to see how denying entitlement to these deaf children can be ‘targeting the benefit at those most in need’.

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 Information about the reform proposals should be available in a variety of formats including BSL, and should be made easily available using electronic as well as traditional methods of communicating.

11. Transitional arrangements
11.1 Whilst we welcome the Government’s decision to have a different commencement date for children and working age adults for PIP we are concerned that the policy as it is written may result in deaf young people when they turn 16 ‘testing out the new system’. This will happen because DLA awards for young people generally expire and have to be renewed on the young person’s 16th birthday. We are also extremely concerned that the assessment process for PIP is not suitable for deaf young people under 18, as outlined in section 7.

11.2 As part of the reforms to the education system all young people will be required to participate in some form of education or training until they reach the age of 17 in 2013 and the age of 18 in 2015. As a result, it is clear that it no longer makes sense for disabled young people to be moved onto a ‘working age’ benefit at the age of 16.

11.3 In order to address this, to ensure that the 16 year olds do not test the new PIP system in 2013 and are not subjected to a highly inappropriate assessment process, we recommend that in consultation with young people the department considers raising the age at which disabled young people are moved onto working age benefits from 16 to 18. Deaf young people turning 16 from 2013/14 should continue to receive DLA until they turn 18.

11.4 This measure would ensure that disabled young people in 2013 do not become new customers for PIP until they are 18. On turning 18, they should receive specific support to ensure a smooth process between DLA and PIP which supports their transition to adulthood.

11.5 Additionally to mitigate the impact of disabled young people being the first people to ‘test out the system’ we believe that disabled young people aged 18 – 25 should be the last people to be assessed for and moved onto PIP from DLA under the migration strategy.

11.6 We therefore urge the Select Committee to explore the possibility that deaf and disabled young people turning 16 from 2013/14 should continue to be able to claim DLA as at present until they turn 18.
Written evidence submitted by Headway – the brain injury association (PIP 37)

Background info on Headway and also links to the UN Convention on rights for Disabled people (UN CRDP)

About brain injury and Headway

1. Each year an estimated 1 million people attend hospital in the UK following head injury. Of these, about 135,000 are admitted to hospital each year as a consequence of brain injury. It is estimated that across the UK there are around 500,000 people (aged 16-74) living with long-term disabilities as a result of traumatic brain injury. The most common causes of traumatic brain injury are road traffic collisions, accidents during leisure or work, assaults and falls.

2. Added to this, there are many thousands of people living with the effects of acquired brain injury from other causes such as stroke, haemorrhage, meningitis, encephalitis and brain tumour.

3. The effects of brain injury are wide ranging and can result in complex physical, cognitive and social disabilities. Individuals may also experience changes in emotions and behaviour and may lack awareness of how they have been changed by their brain injury, making it very difficult for families to cope.

4. Please see the appendix at the end of this consultation for further details.

5. Headway is a national charity that aims to promote understanding of all aspects of brain injury and provide information, support and services to individuals with a brain injury, their families and carers.

6. A network of 117 local groups and branches operates across the UK, providing a wide range of services including rehabilitation programs, social reintegration, outreach, carer support and respite. Nationally, Headway UK provides support to groups and branches and helps to deliver high-quality services through guidance on policies, procedures, standards and training. We also have a free national helpline, which provides support, information and signposting to appropriate services.

7. At the time of the Work and Pensions Committee inquiry into proposals to replace DLA with PIP, Central Government have just completed a consultation on the UN Convention on Rights to Disabled People (UN CRDP) and where appropriate we have made links to Convention and the articles contained within.

Welfare Reform
8 The replacement for Disability Living Allowance (Personal Independence Payment (PIP)) aims to cut the amount paid to working age adults by 20%, but it is likely that many more than 20% of disabled people will be subject to loss of this benefit because of new eligibility assessment measures and a change from three to two main rates of payment\(^1\) (that continue to include both care and mobility components)\(^2\).

9 The DWP’s proposed assessment criteria for the new PIP takes wider provision into account e.g. it looks less at the ‘ability to walk’ and more at the ability to ‘get around’; e.g. if someone can use a wheelchair independently, they would be deemed to have the ability to ‘get around’. It neither factors in costs of procuring nor maintaining manual aids e.g. equipment used to transfer from wheelchair to chair, the wider environment or the effects on the person using them (articles 19 & 20). It also takes no account of aids such as cars or scooters that a disabled person may need to live an active and independent life – aids which DLA currently supports.

10 Importantly, the new benefit still takes very little account of a person’s cognitive disability with regards to their ability to get around – someone who is physically very able can easily be incapacitated by their cognitive problems, meaning they are unable to plan, initiate and complete a journey without continual support.

11 A key concern we have heard is that the new PIP may provide for disabled people to ‘survive’, but not to ‘live’ (see, 2.9).

12 Work capability assessments have been criticised because they do not take into account mental health and fluctuating conditions as well as physical impairments. There is fear that the new PIP assessments will do the same.

13 Other categories in the proposed criteria also would also ignore effects or costs associated with impairments/conditions, by focusing narrowly on tasks that would restrict independent living. The criteria fail to consider reductions and constraints on other budgets and the individual freedom afforded by DLA currently, to top-up/purchase more suitable provision than is available through statutory organisations (Articles 5 and 28).

14 A recent report published by the Citizens’ Advice Bureau (CAB, 2011) provides evidence and testimony on unfair and inadequate health assessments undertaken through Work Capability Assessments for Employment and Support Allowance (ESA). ‘Scottish CAB have advised many clients who have been found fit for work in their work capability assessment despite suffering from serious health conditions and face major barriers to work…Bureaux have reported a worrying trend where clients who win their appeal [to have the decision that they are fit to work

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\(^{1}\) At the time of writing the impact of the change from three to two rates of pay remains unclear, and this is further complicated because the DWP have not yet allocated scores to the descriptors to be used to assess claims, which will differ under each category.

\(^{2}\) Emergency Budget ‘Budget 2010 policy costings’ HM Treasury, June 2010
overturned] are quickly given a new assessment and found fit for work again or are repeatedly re-assessed’. 3 This puts people whose health is already frail at risk of deteriorating (a clear breach of the right to rehabilitation contained in Article 26), and could potentially also affect the levels of care support provision that people receive due to the impact the change may have on their DLA (PIP) and Local Authority funded support.

15 Other concerns raised amongst people with a disability about the work capability assessments surround the inherent ambiguity in how the DWP monitors, and cost-recovers from, the companies when decisions are successfully appealed by claimants. There are concerns that this will carry over to the management of DLA/PIP assessments. They further feel disadvantaged by the government on this, when they stand to lose income themselves. Related to this is the targets system that assessors will use for PIP, which, for the work capability assessments, have resulted in far more people being removed from incapacity benefits than the government predicted (69% as opposed to a projected 49%). As many as one in five working age recipients of DLA in Scotland may stand to lose their benefits when the new assessments take place. The high numbers of people moving off Incapacity Benefit through current work capability assessments include mistakes reflected in the high rates (40% UK wide and up to 70% in Scotland) of successful appeals.

16 Care charges (falling under the Scottish and Local Governments’ remits) reduce disabled people’s available income particularly when they enter employment. The guidance available to local authorities in England allows disabled people to retain more of their earnings when care charges are being assessed. The current care charging guidance in Scotland, taken together with the recent cuts to the Independent Living Fund (ILF), have reduced the income of some disabled people in employment to below Income Support levels (after housing costs, travel to work, etc. are taken into account) (Articles 5, 19 and 28).

17 Disabled people are and will be disproportionately affected by the cuts labelled as ‘welfare reform’, both in terms of their income and the services they receive. Taken in sum, such “regressive government policies seriously undermine the rights of disabled people and the UN [Convention]”. 4

Two rates of award

Setting the rate thresholds

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4 http://www.disabilitynow.org.uk/latest-news2/cuts-threaten-independent-living
18 We notice with some concern that the draft criteria have been written without any statement of the thresholds that will determine which rates a person will be awarded.

19 Many respondents to the consultation expressed fear and concern over the possible withdrawal of the mobility component due to tightening of the criteria, and refer to the ability to use the mobility component to fund a Motability car as their main means to independence. It is often people who currently sit in the middle of the scoring in the new criteria for certain activities who will benefit most from the benefits DLA and PIP bring.

20 Without seeing what thresholds are needed to be awarded the different rates of the benefit it is impossible for us to comment fully on whether these criteria are suitable or not, but we call upon the Government to ensure that, when placing these thresholds, all people who need this benefit are protected. Whilst the simplification of the benefit could, in theory, make it easier to administer, the reduction in the number of components, particularly in the ‘Care’ component, will potentially stop a lot of people who currently benefit from and need the lower rate of DLA from receiving it. The risk is that it will make it less equal and that some people will get a high rate of benefit while other vulnerable, disabled people get nothing. The proposed changes will result in the new benefit being less appropriate to each individual and will result in fewer people being entitled to the benefit.

21 There are concerns regarding the current “main meal” assessment as this is one of the main criteria for awarding benefit and does not accurately reflect the support people with an ABI require to enable them to carry out this everyday activity. Help with planning a meal, supported travel to purchase food and food preparation all require a high level of support. Assessing only the ability to cook a meal does not reflect the high level of support needed to complete this task and is a crude judgement of people’s abilities.

22 Due to the many cognitive impairments that most people with an ABI have, we would suggest that it will be a huge struggle for many people who are unable to process and retain information, to complete the application form without requiring assistance.

23 The application process for DLA is a standard application form and does not provide the scope for people with an ABI to provide information on the level of disability they have. There is also no opportunity to provide information on cognitive deficits - the most common consequence of having a brain injury. It is appreciated that it is unrealistic to have an application form which reflects the full range of medical conditions and/or disabilities; therefore there is a reliance on the assessment process, which many people perceive as being inconsistent, unfair and very often inaccurate.
24 The main reason for lack of understanding of DLA is the inconsistency in the current assessment and award process. There is a strong view that the assessment panels do not have the level of expertise required to assess the complexities of ABI. Also, many people feel that the GPs used to carry out these assessments do not have the required level of knowledge or expertise to make appropriate assessments. This inconsistency impacts on people’s ability to understand the application process rather than the problem being with completing the application form. As such, we would strongly recommend that a neurologist, neuropsychologist or neuropsychiatrist should be a member of any assessment panel involving a claimant with an ABI, in order that an accurate, competent and safe assessment can be made.

25 Having two different levels of award for each component part of the benefit does recognise that people with certain conditions will have varying degrees of similar needs and the amount of benefit should reflect this. Again, unless there is a clearer and consistent assessment, appeal and award process, there will continue to be confusion and lack of public confidence in the process of allocating DLA and the new Personal Independence Payments.

26 By removing one level of award as with the current system, some people with disabilities will lose benefits, which will have a massive impact on their quality of life and their ability to play an active role in their community. As the form very much focuses on the physical aspects of disability (which as already mentioned, not everyone with ABI will have), many people with cognitive problems that affect their ability to get around and participate in society will go unrecognised. We would suggest that it could also be potentially harder for those currently on the low or middle rates to get the benefit at all, which would result in even greater financial hardship for this particular group of disabled people and their carers.

27 People who already claim the lower rates of DLA are awarded the benefit on the basis of need – this need will not go away simply because the lower rate has been withdrawn, but it seems, will simply be ignored.

**Automatic entitlement and indefinite awards**

28 We think it would be fair to assess each claim on the basis of need, as long as the assessments are carried out equitably by professionals with the relevant clinical expertise in the condition concerned. If someone has an obvious condition which is regarded as a long term condition and the prognosis for that condition is that it will not improve with time, then we would suggest that reassessment is clearly not necessary.

Additional comments from our service user panel
29 What can improve in the longer term is how people with these conditions learn to cope with their disabilities, and DLA has been instrumental in improving people’s quality of life by allowing them to have the financial freedom to lead a more independent life. People who have sustained an ABI will not always be able to regain certain brain functions; therefore the cognitive and mobility deficits will not be regained through time. People with an ABI will also require ongoing support both from a physical, emotional and psychological perspective with their disability being life-long condition. As such, there should be automatic entitlement to DLA and the new Personal Independence Payment. As already mentioned throughout this document, an ABI has a massive impact on energy levels, ability to concentrate, anxiety, memory, planning functions etc, all of which are “hidden” impairments that are difficult to demonstrate on the current forms. If an individual’s brain injury is severe and there is little chance of further improvement, there should be no requirement to have continual assessments and reviews, which cause undue stress and anxiety for people with long term medical conditions, their families and carers. Repeated, unnecessary assessments also incur an additional higher financial cost to the DWP which is money that could be saved and used far more efficiently and effectively.

Qualifying period

30 We believe that the length of time from application to securing DLA payment is unacceptable. The proposal to have a six months qualifying condition does not reflect the fact that some medical conditions have an instant impact on people’s ability to (return to) work and function normally. For some conditions such as ABI the medical prognosis is straightforward and depending on the severity, these conditions should not have to meet the six months qualifying period. The length of qualifying period also causes undue financial pressures for carers and families and makes life even more of a struggle, exacerbating the impact of the ABI. This additional financial pressure can often lead to further anxiety, debts, family break-ups and mental health issues.

31 The impact of a 6-month qualifying period also has a huge impact upon many family members who instantly become carers following a trauma. Many have to give up work to assume a caring role and therefore the financial burden is immediate.

Passporting

32 It is essential that the new PIP retains the passporting that benefits so many DLA claimants today. Schemes such as disabled travel cards and Motability are key reason why many disabled people are active members of society, and withdrawing these services would condemn thousands of people to a life of poverty and reliance on social care services.
33 There is an inconsistency in allocating bus passes, and only those who qualified for the middle and higher components receive bus passes. For those people with a disability who can access public transport, the travel card has huge benefits, and assists people to get out and about at a reduced cost. For others who have used their mobility component to fund a car, this has greatly increased their independence to get about and remain more active. It would useful to review the issue of travel cards with the introduction of the new benefit; as part of the assessment process it should be established if applicants are able to use public transport and would wish to access a travel card. This would lead to greater social inclusion and opportunities for increased independence.

34 DLA and the new PIP should be a passport for free prescriptions and eye care as currently only those people on income support receive free prescriptions and eye care. DLA and the new PIP is a benefit which recognises that people have a medical condition yet those who live outside Scotland are required to pay for their own prescriptions and eye care.

35 Many people with a long-term condition will require to take medication for long periods of time and the cost of their medication can often be a financial burden. Given the fact that DLA is a benefit based on people’s medical needs, is it not appropriate that they also receive free prescriptions and eye care? ABI is a condition which can very often require people to take various types of medication for life; some people who have sustained ABI also have problems with their vision which will require ongoing medical treatment and support. Given that ABI results in restricted mobility and also can have an impact on core body temperature particularly if the pituitary gland has been damaged, it would also seem appropriate that people in receipt of DLA or PIP are automatically entitled to the winter fuel allowance.

**PIP assessments and delivery**

**The independent assessors**

36 As already mentioned we are extremely concerned about the lack of expertise of the assessors for PIP. We would like to see only clinicians and medical staff with specialist knowledge of acquired brain injury assessing people in this group. We are certain that many medical professionals, such as General Practioner’s, have very little or absolutely no knowledge whatsoever of this complex condition, and of the cognitive, psychological and behavioural effects, which are often not visible.

37 It is also vital that the opinions and statements from treating medical professionals and/or family members are taken into account, as in the case of ABI in particular, many people lack insight into their own condition. This will make them unable to answer questions accurately, resulting in a high risk of an inappropriate award being made. In all cases we would recommend that the person being assessed is urged to bring a carer, family member, and friend or advocate who can assist in the assessment process.
38 We are also extremely concerned about the level of independence of the assessors, and whether they will be given targets for rejecting claimants given the proposed 20% reduction in claims.

Assessing brain injury accurately

39 While we welcome the addition of a number of criteria that take cognitive deficits into account, we feel this should go further to take account of the many behavioural and psychological effects of brain injury, plus the more complex cognitive problems people experience.

40 Fatigue is one of the most debilitating yet hidden effects of brain injury, and yet there is no mention of this in the draft criteria. As an example, given the varying picture this symptom creates, an assessor could visit a claimant in the morning and make a judgment based on their ability at this time, unaware of the serious impact that fatigue levels later in the day could have on their performance.

41 This applies to the common symptoms of poor motivation and lack of insight too, so for example a person might be able perform a task, but would have no motivation to do it, or insight into why they should. How will the Government ensure that this is taken into account in order to protect the most vulnerable people in our society?

42 While we appreciate that many symptoms of brain injury are taken into account much more than with DLA, we still feel the criteria will leave large gaps in the full assessment of disability. For example, greater emphasis is needed on the effects of communication problems caused by cognitive functional deficits, and also the complex and wide ranging memory problems that result from a brain injury.

43 We can see a large gap in the criteria where the basic activities of daily living are not being assessed. This includes sleeping, breathing, relationships and sexuality, none of which are being considered anywhere in the proposals.

44 There is also an important category missing from the criteria – an individual’s ability to maintain positive physical and mental health. This needs to take account of their ability to use services such as dentistry, opticians, chiropodists, counselling and local community mental health/acquired brain injury teams.

45 It is also important that the Government is sensitive to the stress that a benefits assessment can place on claimants; particularly in the case of brain injury where focusing on the negative aspects of a trauma can have serious psychological consequences, possibly leading to exacerbation of symptoms and/or additional behavioural problems.

Safeguarding
We do not feel that the safeguarding agenda is implicit throughout the activities to be assessed. While the benefit assesses a claimant’s ability to perform basic everyday tasks, it makes no mention of their ability to protect themselves against all forms of exploitation, for instance from financial, physical, psychological and sexual abuse.

**DLA/PIP – children and adults over the state pension age**

Headway provides support to adults with an acquired brain injury and therefore do not have the level of expertise or knowledge to respond to the question regarding children.

We would however comment on the proposal for people over state pension age and argue that age should not be a factor in the PIP assessment process. Acquired brain injury has a devastating effect and access to disability benefits should not be discriminatory.

**Communicating the reform proposals**

People who are currently in receipt of DLA will have an understanding of the eligibility of the new benefit and prior to the introduction of Personal Independence Payment they should be advised of the changes in the assessment process and levels of award. Benefits advice should be available in GP surgeries, hospitals and social services departments, especially when people have sustained an injury which is likely to leave them unable to return to work, or if an injury will result in the person requiring ongoing support and care. Hospital Social Workers, where accessible, should also be able to signpost people onto benefits advice if they themselves are not able to provide it. Benefits advice and support should also be included in hospital discharge plans, if the person has sustained an injury which will result in a long term medical condition such as an ABI. There should be clear referral processes established in neurological wards of hospitals, as these patients are the most likely to be unable to work and will have to rely on DLA (PIP). Patients, and more often than not, carers, should be given contact details of independent benefit advisors in their local area. One suggestion which would also assist this process would be to hold benefit surgeries periodically within these specialist hospitals.

The difficulty in providing information as to who is likely to get the benefit results from the inconsistencies in awards.

All benefit information must be written in plain English language, with clear information about what the qualifying conditions are and identifying the components parts to the benefit, and the levels of award. Definitions of mobility and care should also be given in the information with examples provided.

Better training for the people who administer the benefits on what’s available and on different conditions (as well as where to access expertise and advice on
specific conditions). TV advertising, information left in hospitals, CAB, community projects (Third Sector organisations), libraries etc.

**Transitional arrangements**

53 We would propose that people who are currently in receipt of DLA should have their case reviewed without the need to attend a re-assessment. The review should focus on whether or not the condition is recognised as a long term (disabling) condition and unlikely to result in significant improvements. Expert advice should be sought from medical professionals i.e. neurologists, on the likelihood of there having been major changes to peoples level of disability and we would recommend that as an ABI is recognised as a long term condition then these claimants should automatically be transferred to PIP.

54 New claimants should go through the assessment process to establish if they have a recognised long term condition, and, if so, then a paper based assessment should be completed. For claimants who have a fluctuating medical condition an assessment might be appropriate, but only to ensure that a fair award is given based on their ‘worst day’.

**The tendering of DLA/PIP assessment contracts**

55 We would recommend that the assessment contract include a penalty clause for flawed assessments. There is a volume of evidence* which identifies that at least 80% of claimants, who have been wrongly assessed as fit to work, win on appeal.

56 Currently ATOS are paid for what can only be viewed as “flawed or incorrect” assessments which incur additional costs, as these cases are then referred to an independent appeal panel. Given that the replacement for Disability Living Allowance (PIP) aims to cut the amount of PIP paid to working age adults by 20%, it is our view that if 80% of assessments are flawed, the introduction of penalty clauses would assist in improving accuracy whilst decreasing unnecessary costs. The other alternative would be to withhold or remove payment for flawed assessments, and these savings then going towards assisting the Government in meeting the budget deficit, rather than cutting the payment of PIP to disabled people.

57 From our consultation on this issue, we know that public confidence in the current and proposed assessment process is extremely low and is in the main due to the high number of claims which are referred to the appeal panel, and as previously mentioned 80% of these cases will be upheld.

Applying the above suggestions would result in the reduction in the number of flawed assessments, whilst also greatly reducing the number of appeals required, and this in turn would go some way to restoring public confidence in the assessment process. If the assessment process resulted in more accurate awards this would also greatly reduce the level of stress and worry that claimants and their carers have to face.

Conclusion

In assessing the draft criteria, many of our service users who currently claim DLA felt that reducing the assessment to just a few tasks left out many of the essential daily activities that they are unable to perform.

A stated principle of PIP was the process being more active and enabling, however this does not seem to be the case within the proposed assessment criteria itself. Headway does not feel confident that the numerous cognitive, emotional, psychological and behavioural effects of brain injury are being taken into account across the 11 proposed activities. For example they do not take account of problem solving, fatigue, memory problems, comprehension and cognition, anger, sexual problems, sleep disorders and safeguarding issues.

Headway service users involved in this consultation spoke about the growing stress and fear of the unknown and the thought that genuine cases will lose out. Respondents also felt that their input will not play a significant part in influencing the draft assessment criteria consultation, something which clearly shows the lack of confidence in the whole process. We would be particularly interested to learn how the Government will judge the success of this new benefit, and under what criteria it will be judged against?

We believe that if the Government is to achieve its aim of producing a fairer benefit to help vulnerable people access greater independence, it is vital that, the issues raised within this consultation response are taken fully into account.
Introduction

1. This evidence submission from ecdp is informed by the lived experience of our members. This was received through:
   - A specialist pan-impairment reference group of 12 people
   - A focus group of 22 people
   - An online survey, which received 50 responses over 10 weeks
   - Other information received from members during ecdp’s work with disabled people in Essex and further afield.

2. Our submission follows the areas of interest outlined by the Committee in the announcement of its Inquiry.¹

3. Our submission includes references to findings previously submitted to DWP as part of their consultations on Disability Living Allowance and Personal Independence Payment. For ease of reference, both previous papers are attached separately.

The need for reform

4. ecdp recognise that DLA is a system of support for disabled people that is in need of reform.²

5. Having been introduced in 1990 and implemented in 1992, many parts of the system, which now serves many more disabled people than it did in its infancy, do not work as efficiently as they could. Inconsistency and a lack of transparency in the way eligibility is determined for DLA means it remains one of the benefits disabled people can access most shrouded in uncertainty.

6. While recognising this need for reform, ecdp supports the decision to maintain DLA as a non-means-tested, non-taxable, non-NI contributions dependent

² [DWP - Government’s response to the consultation on Disability Living Allowance reform](http://www.dwp.gov.uk/docs/dla-reform-response.pdf)
benefit, and also that it will continue to be recognised as a "passport" to many other publicly-funded benefits and services.

Increase in DLA caseload and expenditure

7. It has been noted many times during the progression of the Welfare Reform Bill that the number of disabled people claiming DLA has risen steeply in recent years:

   It is important to bear in mind that in just eight years, the number of people claiming Disability Living Allowance has risen from 2.5million to 3.2million – an increase of around 30 per cent.3

8. Of course it is not possible to definitely identify the exact causes for the rise in claimants. However some obvious factors include the growth of general population and more specifically a population that is getting older.

9. One clearly related factor is the positive steps taken in law (Disability Discrimination Act 1995, 2005 and Equality Act 2010), and more generally to recognise a range of conditions within the definition of disability, including long term health conditions. Whilst incorporating these conditions into the PIP assessment criteria is unquestionably the right way to address this, doing so will rightly mean a rise in the number of individuals entitled to claim. Due consideration needs to be given to how these people will then be supported by the PIP benefit.

Implications of a reduction in expenditure

10. While welcoming the assertion that DWP has ‘sought to develop an assessment which considers and reflects a broader range of impairment types than Disability Living Allowance.’4, ecdp and our members are concerned about how this will work in practice, in the context of budget restrictions.

3 PIP policy briefing note: Introduction (point 18)
4 PIP initial draft of assessment criteria – technical note (point 1.4)
11. It is essential that PIP and the way it is administrated reflects all disabled people eligible to claim and takes account of the different barriers individuals might face as a result of these.

**Focus on need (the “demand” side)**

12. By focusing only on need, the reform risks turning DLA into a health and care budget by proxy, rather than focusing on those people with the highest costs. As such, it is positive to see that PIP, like its predecessor, aims to meet the extra costs disabled people face.

13. Our concern is that while cost is viewed as directly related to need – when evidence suggests there is in fact no correlation — and therefore uses an assessment which only examines need as a way of measuring both (using ‘proxies for the impact of a health condition or impairment including costs arising from disability’) those with extra costs will not be supported by PIP in the way the above suggests they should be.

14. As such, members are worried that they will be penalised for a higher level of independence. If someone can complete the tasks the assessment requires them to fully or without support, it is still quite possible that they could face extra cost in doing so. However, currently, this would not be reflected in the proposed assessment.

15. We know that DLA has enabled thousands of disabled people to overcome additional barriers by providing for the cost of overcoming them. Through earlier work with members a very clear outcome of this is equal participation, including in the workplace. Though DLA has never been an out-of-work benefit, it does provide a platform for disabled people to get on in the workplace and prevent people from requiring more support later on:

> Without my DLA I would lose my adapted car, my independence and my job. DLA supports me to contribute because it enables me to work full time.

5 Counting the Cost, Demos: [http://www.demos.co.uk/publications/countingthecost](http://www.demos.co.uk/publications/countingthecost)

6 PIP initial draft of assessment criteria – technical note (point 4.4)

16. It is no less than essential that PIP continues this progress, and it is only through maintaining provision for cost that this will be the case.

**The supply side**

17. DLA and the current reforms focus on the *demand*-side of the equation, i.e. the requirements of the individual. We take the view that this can only therefore be one part of the solution.

18. However, amongst other areas (e.g. employment, transport and housing) we feel there is considerable room to influence, shape and drive down the additional costs relating to disability on the *supply*-side of the market.

19. For example, provision within the social care market in response to the personalisation agenda and Personal Budgets / Direct Payments is relatively slow. However, significant market-shaping work continues to accelerate, and learning from this is available that could benefit wider provision of goods and services beyond a social care and health setting.

20. We thus feel there is a significant opportunity to be taken up to do more market-shaping work in the time leading up to the introduction of a reformed DLA system that can both drive down costs relating to disability on the supply-side and potentially stimulate an increase in disability-related business activity.

**Funding overlaps**

21. In our original response to DWP’s DLA reform consultation⁸, we noted concern about “cost shunting”: shifting public expenditure away from DLA monies and to public budgets elsewhere. We concluded both that there is value in the concern the mobility component proposal affecting residential settings has attracted.

22. We also noted that the assumption that aids, adaptations and equipment are now part of the general landscape of provision for disabled people is not correct. The ultimate cost of providing equipment will have to have been met from somewhere, and this could equally be NHS, social care or private money. As such, if an identified need isn’t met at the earliest opportunity - which DLA often represents - then the costs of meeting a later need could potentially

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become bigger, but for a different budget. As such, we called for reassurance that coordination between DWP, DH and local government (as social care) as a minimum is in place as a result of these reforms.

Automatic entitlement

23. With an awareness of DWP’s aim for efficient systems, which are more straightforward to administrate and simpler for the individual to navigate, we feel that there are some cases where automatic entitlement might be most appropriate.

24. Likewise, given the move away from indefinite ‘life-long’ receipt of DLA and towards fixed term PIP awards, we feel it is essential that review periods are proportionate to likelihood of change in the individual’s impairment and or life circumstances.

25. Our members were supportive of an approach to both entitlement and review which reflected the nature of their impairment and the likelihood of change. Indeed, 86.5% of those who responded to ecdp’s online survey agreed that the process the claimant goes through should depend on their impairment and in some cases automatic entitlement could be the most appropriate result.

Qualifying period

26. We find the alignment of the definition of those who are potentially eligible to claim PIP with the legal definition of disability (as per the Equality Act 2010) broadly favourable.9

27. However, the experience of DLA users we have consulted with suggests that the ‘other financial and in-kind support mechanisms’10 available in the shorter term are not always easy to access immediately. This can leave people without the required support. For example, one claimant had a contact who had

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9 DLA reform consultation: ecdp response (point 15)
10 PIP Policy briefing note: Required period condition (point 1)
…been left struggling financially and feeling very isolated as she could not leave her house without assistance.11

28. 43% of survey respondents were not aware of any financial or in-kind support they could access and a further 13% had tried to access other support while waiting to claim DLA but were unable to. Significantly, 42% of respondents had faced problems during this period while waiting to claim DLA.

29. The high number and severity of issues faced by disabled people waiting to claim needs to be considered. The resulting financial hardship has potentially huge impacts on the health and wellbeing of the claimant and therefore has cost implications for other services, notably the NHS.

30. While waiting to be entitled to claim DLA, members reported experiencing Severe and worsening disability with increasing costs and decreasing income.12

31. It is therefore our proposition that whilst the twelve month total of the qualifying period and the prospective test seems sensible, this does not necessarily need to be set at six months each, especially in cases where the impairment will definitely be long term, or indeed permanent.

Gateway / passport benefits

32. For many of our members the benefits that DLA acts as a gateway for are as important as the benefit itself. Most commonly, members converted their mobility entitlement to accessing the Motability scheme.

33. Furthermore, members had used DLA to qualify for discounts on social activities, for example football or theatre tickets, as part of offers given to DLA recipients. The importance of being able to use DLA to access the same activities as non-disabled peers was emphasised.

34. As the government looks towards PIP as a replacement for DLA, ecdp are in favour of these passport mechanisms being kept.

11 ecdp PIP reference group member
12 ecdp DLA/PIP survey respondent
Assessment

The design and delivery of the PIP assessment

The new assessment to determine entitlement will be fairer, more transparent and objective. It will provide individuals with the opportunity to explain their individual circumstances and for independent assessors to clarify points with them.\(^\text{13}\)

35. In terms of involving disabled people – as discussed above – some clarity around what a ‘transparent’ system will entail and how disabled people will be involved in establishing and maintaining this would be useful moving forward.

36. One key issue within this is the ‘trained assessors’ that will be used. Our members felt that it would be useful to have a clearer understanding about what training they would have, and whether this would be impairment specific.

37. A general consensus expressed in the reference groups was that where assessors would see individuals with all impairments, they should have strong training around disability equality and communication skills.

38. The results of ecdp’s survey demonstrate this is a feeling held more widely: given the option to select as many types of training as they felt should apply, 89.2% survey respondents stated that assessors should have communications training and the same number of people felt that they should have disability equality training. 86.5% would like the assessor to have specific knowledge about the impairment of the individual.

39. Some concern was raised around how assessors working within an objective system will also adequately take account of the different life circumstances of claimants and their different impairments. Further expansion on how this would be assured through the training would be useful.

40. Many members feel that assessments should either be conducted by, or take account the opinions of, GPs or consultant specialists. 79.4% respondents wanted a GP involved with their assessment and 82.4% had provided supplementary information from a doctor or consultant previously.

\(^\text{13}\) PIP Policy briefing note: Delivery – the operational approach (point 2)
Listen to my doctors! They see me a lot more than any assessor would, and my condition is not visible to the untrained eye.  

41. However, for others who perhaps did not regularly need to see a GP or consultant for the long term management of their impairment, different professionals such as social workers or carers were their preferred ‘expert’.

Social services [should be involved] as they did an assessment of my care needs.  

42. Some felt that a system of self-assessment would be a more empowering approach, and one which places the claimant in a position of control over their own support. Indeed, evidence suggests that self-assessment within social care leads to both better outcomes for service users and better use of public resource.

43. It was felt that this style of assessment, not only more person-centered but more flexible in its methods, gave a more accurate impression of the disabled person as a whole. For example, some reported not being able to paint a true picture of how their impairment affects them in the short time available:

An assessment of blindness cannot be made in a forty minute appointment. A day is needed to show how blindness affects every day life.

44. As part of this wider view of the disabled person’s life, some members would like to be able to submit other evidence, for example diaries or photographs:

I need for my written statements, composed over time, to be taken as my evidence, because my medical condition means that spontaneous verbal evidence is unlikely to be accurate.

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14 ecdp DLA/PIP survey respondent
15 ecdp DLA/PIP survey respondent
18 ecdp DLA/PIP survey respondent
19 ecdp DLA/PIP survey respondent
45. Some also wanted those around them, although not necessarily professionals, or those involved in their care or support, to be involved in their assessment. For some this was a family member (58.5%) or a friend (47.1%).

46. Members feel that the process for the assessment itself was unclear and that they should be made aware of the more specific details around how the assessment would work in practice. For example, it was felt that the number of points allocated to each of the criteria should be made available.

47. Additionally it was thought that it would be useful to give the disabled person an opportunity to view the questions in advance to allow them to think about answers that would accurately reflect their situation:

   The client should have the opportunity to read the questions beforehand. This would hopefully mean that the assessor will get an answer which reflects the need.  

**Communication**

**Communication with Disabled People**

48. The policy briefing note ‘Delivery – the operational approach’, states that DWP:

   …want to ensure that Personal Independence Payment will be simple for the claimant to claim and efficient for the Department to administer.  

49. **ecdp** members are naturally supportive of a move towards making the entire process – from application to review – easier to navigate and therefore generally more accessible.

50. Specifically, the recognition that ‘the DLA claim form is too long and complicated’ and the assurance that DWP will work actively ‘to design an improved form that is understandable and as straightforward as possible’ are positive steps towards addressing issues that many members raised with respect to written communication.

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20 **ecdp** PIP reference group member  
21 PIP Policy briefing note: Delivery – the operational approach (point 1)  
22 PIP Policy briefing note: Delivery – the operational approach (point 18)
51. Members agreed that forms were often too complex and there was a feeling that a number of the questions asked were unnecessary as they had previously shared this information.

Every time you [update you] get more and more, it gets thicker and thicker.\(^\text{23}\)

52. Not only is a complex form an initial barrier for applicants but the strict expectation on style of response can create unnecessary stress for the applicant, and unnecessary admin for DWP. Indeed, a number of disabled people who contributed to this work had been rejected when applying for the first time, simply because it was not clear what information they should be providing, or how it should be presented. When they received guidance from a professional or advocate who could advise on the correct presentation of the same information, their claim had been successful:

I had to appeal because I did not put it in a way that the DWP wanted.\(^\text{24}\)

It took years of practice until we worked out how, in my case, to explain my situation in terms Decision Makers could understand.\(^\text{25}\)

53. It is important to note that overly complex information is not just a barrier to those with impairments that affect the way they communicate or understand information, but to all individuals. Indeed, 20.5% of survey respondents said that the current system was not accessible to them. This issue was also emphasised above all others relating to communication by ecdp’s PIP reference group.

I found and find the current application system extremely complicated and extremely inefficient.\(^\text{26}\)

54. Therefore, as DWP look to do further work on setting up ‘multiple channels through which disabled people and their carers will be able to access Personal Independence Payment information…’\(^\text{27}\) due consideration needs to be given to

\(^{23}\) ecdp PIP reference group member  
\(^{24}\) ecdp DLA/PIP survey respondent  
\(^{25}\) ecdp DLA/PIP survey respondent  
\(^{26}\) ecdp DLA/PIP survey respondent  
\(^{27}\) PIP policy briefing note: Delivery – the operational approach (point 17)
the availability of the information needed at every stage of the process in a variety of formats. Attention to the individual’s preference in terms of format early on in the process could easily address some of the difficulties members had experienced.

Have as many formats as possible; text in various sizes, Braille, British Sign Language… Also helplines and internet.  

55. The creation of an online claim facility in addition to the paper claim form would certainly open up access options for the many disabled people who use digital technology to meet their access needs in a way that more traditional technologies do not. However, this should not be seen as a replacement for a variety of these more traditional formats given that overall, disabled people are less likely to use the internet due to a number of additional barriers they face including cost, and indeed, accessibility.

[Information should be available] online but also in an easily accessible paper format, without the third degree to get it.

56. Where information is provided online, it would be useful to have some thought around ensuring this is accessible, in the widest sense, and easy to navigate. This had not been the experience of all members:

Make it less difficult to find [information] through their own website it takes a lot of searching and their sites are not the most user-friendly.

57. It was also suggested that making supporting information available in a wider range of places that disabled people regularly access or that are open to the community – such as disabled people’s organisations, support groups, libraries, doctor’s surgeries – could make accessing support throughout the process more accessible, especially during the transition period. However, some also felt that of these, it would be best to make use of those areas where an appointed individual could support or answer any questions.

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28 ecdp DLA/PIP survey respondent
29 Ibid
31 ecdp DLA/PIP survey respondent
32 ecdp DLA/PIP survey respondent
58. Interestingly, many members of the group had accessed support from impairment specific disabled people’s organisations, often because they catered for their specific communication requirements, for example British Sign Language. This reinforces the need for people’s access needs to be met by the department itself, so that they do not have to seek this extra, external support.

59. One member was very clear that advocate support had enabled her to successfully challenge a decision to lower her rate of DLA as she became independent. While hoping to see this support available in the new system, she also felt it was important to ensure that this did not compromise people’s right to a confidential assessment. Interestingly, 61.8% survey respondents would want to have an advocate involved in their assessment.

**Face-to-face communication**

60. The opportunity to communicate face-to-face with advisors and assessors was largely welcomed by members, especially given that some preferred not to use written communication:

   Face-to-face assessment is beneficial for those who find it difficult to fill in forms.  

61. 28.9% of survey respondents had accessed initial information about DLA through face-to-face, and 41.2% had face-to-face consultations as part of their assessment.

62. While welcoming an in-person approach, members were keen to stress that this should not necessarily be a medical examination and some members were worried that face-to-face meetings can lead them to feel out of control. Care would need to be taken to ensure this process was user centred, “like support planning”

63. As previously mentioned, some members had very negative experiences of “not being listened to”, some of which had resulted in incorrect decisions about their

33 ecdp DLA/PIP survey respondent  
34 ecdp PIP reference group member  
35 ecdp PIP reference group member
DLA award. With a move towards a largely in-person approach to assessment, this must be addressed to ensure that people are given adequate time to think about what information they need to share, to explain this in their own words, and feel that this is being accurately recorded:

I valued having time to think about my responses, especially as my condition fluctuates.  

Notifications

64. Members of the group felt that regular notifications, both throughout the initial application process and if any changes were to take place thereafter, would be useful:

DWP should keep you updated with the changes as and when they happen.

65. They also reported feeling that after sending information there was a long wait before any update was received. Therefore we welcome the move towards ‘improved notifications’.

Communication with the general public

66. Many ecdp members have expressed concerns at the rhetoric around benefit reforms. It is important that the facts around DLA reform are communicated clearly, not only to those directly affected but also to the wider population, to ensure that the benefit itself and the reason for the reform are understood.

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36 ecdp PIP reference group member
37 ecdp PIP reference group member
38 PIP policy briefing note: Delivery – the operational approach (point 16)
Written evidence submitted by Scope (PIP 39)

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.1 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%.2 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…”3

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

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2 Sen, A The Idea of Justice (Allen Lane: 2009)
3 Survey conducted by ComRes, commissioned by Scope, late 2010. Sample size: 845.
multiple pieces of information (e.g. 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.4

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 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!”5

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 2002-2003, 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.”6 The prevalence of disability has increased, as research shows.7 The number of adults reporting conditions, and apparent increases in autism and dementia should also be taken into account.8 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.9

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4 Wood, C & Grant, E Counting the Cost (London: Demos, 2010)
5 Respondent to survey carried out by ComRes, commissioned by Scope, in 2010. Sample size: 845.
9 Fraud levels for DLA are – at 0.5 per cent – 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)
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%. 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 per cent 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. 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 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 recognize 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

11 DWP Personal Independence Payment: initial draft of assessment criteria – a technical note to support the initial draft of the assessment regulations (London: DWP, 2011)
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 3 to 6 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 – i.e. 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. Regarding the NHS Healthcare Travel Costs Scheme, 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”. 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. 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

14 DWP Personal Independence Payment: initial draft of assessment regulations (London: DWP, 2011)
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, 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 organizations 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 organizations, 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.
Written evidence submitted by Yare Valley and District Citizens Advice Bureau*  
(PIP 40)

General: The decision of the DWP Select Committee to look into this issue is welcomed. We are not aware of its timetable but assume that it is very tight given that the Bill is about to enter its Lords stages. The Committee no doubt intends to influence the secondary legislation stage where most of the detail will occur.

Our comments on the questions raised are:

The need for DLA Reform including how well the benefit is understood, why case load and expenditure has increased, the effectiveness of the decision making and review process  
DLA is now 20 years old and since it was introduced advances in medical science have ensured people’s survival and indeed prolonged people’s lives. This alone warrants the review of the benefit as those advances will have had both positive and negative impacts on the ability of people to function following survival. Many will be living with considerable disabilities, with consequent additional expenditure for them and their families as well as opportunities to improve their long term prospects foregone. This will also have had an impact upon the case load and consequent expenditure.

As to the effectiveness of the decision and review procedure we are concerned about both, particularly the medical assessment considerations and initial rejection rates. This also produces considerable and often avoidable expenditure with the need for review and appeal. Further consideration does need to be made about who provides the medical assessment and to ensure they are fully aware of the policy intentions behind the new benefit.

Introduction of the benefit should provide the opportunity to be clear to the public what it is and is not intended for. This particularly in that there is a sense of returning to the old AA rationale: i.e. a 6 month qualifying period, a focus on the effect of the disability on ability to function rather than any particular condition acting as a passport to the benefit and two rates of benefit.

The implications of a reduction in expenditure, the implication on focusing on those with the greatest need, Two rates only of PIP, and the numbers who would not be eligible. If this is a cost cutting measure only – 20% has been mentioned – then there will be losers and some consideration will be needed as to how any gaps might be filled particularly for the vulnerable and/or on limited income. There is potential for a real loss of income for those at the lower end of the income scale, and those who care for them.
The extent to which funding overlaps, particularly with LA and NHS funding, exist. As funding is tight there should have been a longer opportunity to rationalise benefits and allowances across all providers. There will be real hardship if a race to the bottom ensues given that all sectors are tightening their belts.

Whether automatic entitlement should apply and also indefinite payments. The DS1500 terminal illness provisions should continue. Indefinite payments should be made where it is clear there is unlikely to be an improvement (e.g. those with impairments which acclimatization and the appropriate aids will not improve).

The implications of the 6 month qualifying period. As already mentioned this was the old AA “long term effects” provision. If it is to be resuscitated it needs to be fully explained. Transitional arrangements will be needed given also the effect e.g. on carers benefit. Our organization supports the status quo 3 month period.

PIP as Gateway to other benefits: this needs further clarification and across all the sectors and for carers too as already mentioned above.

The design of the PIP assessment and the position of adaptations. We welcome the move towards a more holistic approach (e.g. para 4.2 of the technical note supporting the assessment document) but wonder if all the permutations have been considered, particularly in the light of the scoring rational on page 9. To be fully holistic you have to consider the implications of planning and following a journey if you were incontinent and the extra difficulties this would cause. Similarly, ability to manage medication and monitor health conditions must surely merit a higher scoring. If that isn’t right functioning would be impaired.

The effect of adaptations. We are concerned that those who have improved their capabilities through use of aids might be penalised because of those adaptations. There should be no automatic assumption that e.g. an operation will automatically provide a transformation no longer requiring assistance/supervision.

The delivery of the PIP assessment. Some consideration needs to be made to the tiers of decision making and it needs explaining. It is not only the public that is confused. There is clearly considerable distress caused by the current medical assessment considerations, often with seeming little regard for the opinions of claimants’ GPs/consultants for claimants who quite clearly merit an award. The policy intentions behind the benefit need to be fully clear to the assessors and they should be trained accordingly. Just as the work capability assessment is subject to periodic review for the Secretary of State so should PIP if/when it becomes law. Perhaps there is also a role for the Social Security Advisory Committee here?
**How DLA should apply to children and those over pension age.** Given the speed with which this benefit is being introduced there is an argument for bedding it in with those of working age and then considering if it is appropriate for the other groups once all the issues have been resolved.

**DWP and Communication with the public.** If this is to be seen as any more than a cost cutting exercise then a robust rationale for the changes needs to be clarified and publicised. An easier application form would be welcomed.

Additionally, given the number of tiers/ bodies there are between Ministers and their officials owning the policy and third parties/ contractors interpreting on the ground, the former need to retain responsibility for ensuring the two views match. We suspect that a lot of the problems occur because of the number of tiers involved. Minister’s correspondence must surely reflect this.

**Transitional arrangements.** These need to be carefully thought out or their will be real hardship for some of the most vulnerable and their relatives, who often have little choice but to abandon careers and future prospects/financial security to look after them. Some liaison across the sectors would be desirable. We would not expect to see a trend to shorter awards of DLA in the run up to implementation.

**Conclusions**

**PIP should provide Government an opportunity:**

- To be transparent about the policy intentions behind the new benefit and communicate them clearly to the public from the outset,
- To be accountable for those who deliver the benefits so that the policy intentions are kept in mind and there is no mismatch and misinterpretation,
- To provide a holistic approach both within the benefit and across the care provision sector. (Some people do well: too many lose out all round.)
- To simplify the claims process,
- To overhaul assessment system to ensure that more people who are clearly eligible are awarded benefit first time. Too much distress is caused to those challenging decisions and too much money spent on the associated costs. (This is doubly important given MOJ plans to withdraw much current legal aid provision from scope and with cuts in associated funding.)
- PIP should be a matter for periodic review for the Secretary of State.

* Yare Valley & District CAB serves the communities of Wymondham, Attleborough and Great Yarmouth in Norfolk.
About Us

1.1 Macmillan Cancer Support improves the lives of people affected by cancer, providing practical, medical, emotional and financial support. We work to raise awareness of cancer issues and have been campaigning for cancer patients to be treated fairly by the benefits system and given the support that they need.

1.2 We also operate a benefits advice service for people affected by cancer. Specialist Macmillan benefits advisers can provide assistance face-to-face or over the phone and help people affected by cancer work out what financial help they could be entitled to. We currently have 19 advisers operating a welfare rights helpline and 224 advisers working within partner agencies. In 2010, our benefits advisers reached over 60,000 people with financial gains of over £90m.

Summary

2.1 Macmillan recognises the need for reform of Disability Living Allowance (DLA). We know that many aspects of the existing system do not work well for people with cancer. We welcome the Government’s commitment to maintaining the principles of DLA, i.e. a non-means-tested benefit to help cover the costs of living with a disability or long-term health condition. We also support the Government’s ambition to create a disability benefit that is easier to understand than DLA and results in a better service for disabled people.

2.2 However, we have significant concerns that the Government’s ambition to make savings of 20% by 2016 and the proposal to extend the qualifying period for Personal Independence Payment (PIP) from three months to six months will result in thousands of cancer patients with long-term needs not getting vital financial support quickly enough or losing out altogether.

2.3 As a result of treatment cancer patients often experience a sudden onset of daily living and/or mobility needs that can result in significant additional costs that are often long-term. Thousands of cancer patients rely on DLA to help meet these costs at a time when their income has often decreased significantly. Without this support we fear that many cancer patients will be unable to meet the additional costs of living with their condition, which will exacerbate existing issues that contribute to cancer poverty.

The importance of DLA to people with cancer

3.1 As of May 2011 there were 82,400 people receiving DLA who had cancer as their main disabling condition. This total is broken down as follows:\(^{1}\)

<table>
<thead>
<tr>
<th>Care component</th>
<th>Number</th>
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<tbody>
<tr>
<td>All</td>
<td>82,400</td>
</tr>
<tr>
<td>Highest</td>
<td>50,000</td>
</tr>
<tr>
<td>Middle</td>
<td>12,100</td>
</tr>
</tbody>
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\(^{1}\) [http://www.theyworkforyou.com/wrans/?id=2011-02-14a.39124.h&s=dlav+malignant#g39124.0]
Lowest 15,000
Nil 5,300

**Mobility component**
All 82,400
Higher 67,500
Lower 4,000
Nil 10,800

3.2 Qualitative research conducted for Macmillan found that people living with cancer experience a wide range of additional costs (and often continue to face) as a result of their cancer and treatment. These include:

- Hospital car parking and transport costs
- Heating bills due to feeling the cold more
- More expensive diet
- New clothes and shoes
- Aids and adaptations such as stair rails
- Wigs, shoe inserts (orthotics)

3.3 **Travel and parking costs for hospital appointments** – On average someone with cancer makes 53 trips to the hospital costing £325, during the course of their treatment. Low immunity often forces patients who do not have access to a car to rely on taxis rather than use public transport.

> A cancer patient living in Devon had to travel 125 miles to receive radiotherapy on a regular basis. They were out of work because of their condition and due to the cost of petrol they were getting into significant debt and nearly had to give up treatment as they could no longer afford to keep attending. Eventually after a long wait they received support with travel expenses.

3.4 **Heating bills** – Cancer patients often experience increased need for heating (e.g. one in four cancer patients wears outdoor clothing indoors to stay warm and reduce energy bills) and increased need for use of appliances such as a washing machine – due to profuse sweating and hygiene requirements – or dishwasher. One cancer patient explained “because I cannot reach the washing line since having surgery I have to tumble dry the washing”. Over seven in ten (73%) cancer patients undergoing active treatment use more fuel than previously.

3.5 **New clothes** – Due to the effects of treatment many people experience dramatic weight loss or gain.

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2 RS Consulting/Macmillan Cancer Support (February 2011) online qualitative research amongst people living with cancer
3 Macmillan Cancer Support, Cancer Costs, June 2006
4 Macmillan Cancer Support (2009) online survey of 974 people with cancer in the UK.
“Some clothes that I used to wear before my cancer have had to be discarded because I can’t put them on, and some are clothes that hurt my chest if I wear them. I used to wear tiny tight sari-blouses - I don’t any more. I wear t-shirts or pullovers instead, even on the occasions I’m wearing a sari - and yes, it looks odd.” (Breast cancer patient)

3.6 Other costs include aids, adaptations, wigs, shoe inserts, special diets, extra support costs such as delivery charges, petrol costs of family and friends who help with shopping, paying for a cleaner and other ‘hired help’ due to effects of condition and treatment.

3.7 In addition to the onset of additional costs related to their condition cancer patients also often experience a significant fall in income following diagnosis. Macmillan research found that among working age cancer patients (under 55s), 7 out of 10 experiences a reduced household income, losing on average 50%. Also, we know that cancer patients are 1.4 times more likely to be out of work than the general population.

The need for reform
4.1 Currently many aspects of DLA do not work well for people living with cancer. A study exploring the barriers to DLA encountered by cancer patients found that:

- Patients find it difficult to complete the DLA application form, finding it lengthy, repetitive, ambiguous and irrelevant to their circumstances and the specific needs arising from living with cancer.
- Ignorance about the symptoms of cancer and its treatment may make it difficult for Department of Work and Pensions (DWP) Decision Makers, who have not received training on these issues, to assess cancer patients’ entitlement to DLA or Attendance Allowance (AA).
- DWP decision-making is inconsistent, particularly when patients have a disease that is thought to be curable. This can lead to patients’ feeling a sense of frustration and injustice.

4.2 Given this, we support the Government’s ambition to create a disability benefit that is easier to understand than DLA and results in a better service for disabled people.

4.3 However, we are concerned that reforms are been driven primarily by the Government’s plans to make savings of 20% by 2016 and not by the needs of people living with long-term conditions or disabilities.

7 Macmillan Cancer Relief (May 2005) Access Denied: Benefits Advisers’ Perceptions of the problems cancer patients face when claiming Disability Living Allowance and Attendance Allowance
Currently, there are two million people living with and beyond cancer in the UK and this figure is rising by three per cent each year.\textsuperscript{8} As cancer survival rates continue to improve, people diagnosed with cancer will increasingly join people with other long term conditions in living with ongoing support needs. Some people living with and beyond cancer have serious physical, emotional, social problems that need addressing. As a result of these reforms it seems inevitable that thousands of cancer patients who are living with additional costs as a result of their conditions will be left without the crucial financial support that is currently offered by DLA.

It is very difficult to understand how many cancer patients, or whether particular groups of cancer patients, will be worse off as a result of these reforms until more details of the points for the assessment descriptors are published.

\textbf{Daily Living Component}

Again, until the levels at which the rates for the daily living components are published it is difficult to understand which groups of cancer patients will lose out because of the reduction from three to two rates.

If simply the lower rate of care is removed it will be cancer patients who need help for part of the day and help with cooking who are most likely to lose out. In these circumstances financial support provided by the lower care rate is often used to retain independence by, for example, paying for online deliveries, cleaners, pre-prepared vegetables, microwaves etc.

Removing the lower rate care component would have a particular impact on, for example, breast cancer patients who have had the lymph nodes removed and as a result experience restricted arm movement or cancer patients who continue to experience severe fatigue and have difficulty doing many tasks, such as many patients with cancer of the head and neck. As well as the direct financial support provided by DLA, removing lower rate care will also mean than many cancer patient will lose related passported benefits.

\textbf{Qualifying period}

Macmillan has significant concerns about the particular impact that increasing the qualifying period from three to six months will have on cancer patients and other groups with sudden onset needs, such as people with spinal injuries or people who have strokes. Having to wait for three months before receiving DLA is already difficult for people with cancer. Doubling this to six months under PIP will be devastating.

Cancer treatment, and its debilitating effects, can often begin soon after diagnosis. The associated support needs arising from that treatment are often immediate. Importantly, the first six months can be the period when extra costs are greatest as people are trying to adjust their outgoings to their reduced income.

6.3 Nine in ten (91%) of cancer patients’ households suffer loss of income and or increased costs as a direct result of cancer. Without support for the additional costs faced immediately following a sudden onset physical or mental condition, such as cancer, people can face major financial issues such as debt, bankruptcy and house repossession. Often the first three-six months following diagnosis is when cancer patients are on the lowest income as they will be in receipt of Statutory Sick Pay or the lower assessment rate of Employment and Support allowance.

6.4 People with cancer often don’t have access to other sources of support - Some people with cancer will not have access to alternative sources of financial support for the additional costs they face in the first six months of their condition. For many this will result in major financial difficulties and could lead to associated physical and mental health problems. Sources of support, such as NHS travel costs and the Employment and Support Allowance, referred to in the Disability Living Allowance Reform consultation response, are either means-tested or only available to people out of work. Cancer patients could be ineligible for these but could still be eligible for PIP which is a non-means tested benefit which people can apply for regardless of their employment status.

6.5 Benefit such as freedom passes, the Blue Badge scheme and taxi-cards are often only available for someone who has severe long-term or permanent mobility problems so many cancer patients do not qualify especially in the early stages of diagnosis and treatment.

6.6 In order to receive community care grants a person must be in receipt of a qualifying benefit and meet strict criteria e.g. at risk of hospitalisation. Community care grants are also restricted depending on local budgets and are likely to be dramatically reduced following proposed reforms.

6.7 Where cancer patients can access alternative means of support, such as NHS travel scheme, applications are often slow to process, difficult to get paid in advance of appointments and do not help towards cost to relatives and carers who often need to accompany patients.

6.8 Impact of extending qualifying period on debt/financial problems - We already know that due to a sudden drop in income and an increase in costs many cancer patients experience financial difficulties in the first few months of their condition. We fear that these problems will be exacerbated if the qualifying period is extended.

6.9 Macmillan benefit advisers tell us that many cancer patients struggle to pay their bills following diagnosis and often cannot avoid getting into to unmanageable debt. Macmillan research shows that 18% of cancer patients had problems keeping up payments on mortgages and rent following diagnosis and 6% lose their homes9. Often even when cancer patients have mortgage insurance it does not cover the first three months following diagnosis. After three months insurance will often only cover the interest on a

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9 Impact of Cancer 2006, conducted by OLR (Opinion Leader Research) - interviewed 1,751 people.
mortgage. This can lead to significant arrears, reposssession proceedings and in some cases homelessness.

A cancer patient who used Macmillan’s benefits advice service was diagnosed with terminal lung cancer. They stopped work following diagnosis to start immediate chemotherapy and radiotherapy. Their income reduced from £500 per week to around £80 per week. As a result after one month they could not afford their outgoings and could not pay existing credit card debts of £500. Unmanageable additional costs due to their cancer, such as travelling to hospital for treatment, meant that they were unable to pay their energy bills and got into £600 debt with their provider. As a result legal action was threatened.

6.10 Impact of extending qualifying period on treatment - Anecdotal evidence from Macmillan benefits advisers indicates that financial concerns have an impact on the choices cancer patients make about their treatment. Macmillan is concerned that extending the qualifying period will make this problem worse.

6.11 A Macmillan benefit adviser reported that many of their clients had missed appointments, delayed the start of treatment, decided to be treated at hospitals that were not the preferred clinical choice, or have nearly stopped treatment all together because of the difficulty in meeting travel costs. In many cases cancer patients have had to rely on charitable grants in order to afford the cost of getting to hospital.

'I was about to start a new job when I was diagnosed but couldn’t because of my treatment... The extra costs mounted up quickly and were really frightening: travelling back and forth from the hospital, plus the car parking. I also had to buy special bras because of my breast removal. I needed help straight away but I had to wait three months before I could get my DLA. Waiting yet another three months for DLA would have given me a nervous breakdown. I think I’d have gone back to work and not had the operation for fear of going into debt.’ (Karen, breast cancer patient)

6.12 Macmillan believes that people with certain conditions, who face sudden onset of a disability and immediate additional financial costs, should receive an assessment as soon as their needs arise. This would recognise that due to the immediate impact of their condition the costs are often greatest during the first few months and that not getting immediate support can have a particularly devastating impact. We also believe that the three month qualifying period should be retained for all other groups.

Fluctuating conditions
7.1 Macmillan welcomes the approach set out in the technical briefing note published by DWP that in order to satisfy the assessment descriptors applicants must be able to carry out relevant activities "reliably, in a timely fashion, repeatedly and safely, and where appropriate using suitable aids and appliances". We also welcome that the assessment will consider applicant’s ability to carry out descriptors over a period of 12 months. We
believe this will better capture the needs of people with fluctuating conditions, such as cancer, who we know are currently poorly served by the Work Capability Assessment.

7.2 However, it is crucial guidance makes it clear that those carrying out the assessment must consider how a person’s condition fluctuates over the course of a day. We know that due to severe fatigue that can result from cancer treatment many cancer patients’ ability to carry out everyday tasks will change dramatically over the course of a day. For instance, a cancer patient who is able to prepare a meal in the morning may be unable to prepare a meal in the evening.

7.3 With regards to applicants who are awaiting treatment the technical briefing note states that the descriptor choice will be based on the “likely continuing impact of the health condition or impairment as if any treatment or further intervention has not occurred”. Although we understand the difficulties in predicting the likely impact of treatment this approach could be particularly problematic for cancer patients, who often experience significant debilitation as a result of their treatment. Unless their situation is reviewed following the start of treatment it is likely that their real needs will not be captured accurately and they may not receive the rate of PIP that they are entitled to.
Written evidence submitted by ENABLE Scotland (PIP 42)

Introduction

ENABLE Scotland is the largest voluntary organisation in Scotland of and for children and adults who have learning disabilities and their families. We have a strong voluntary network with around 4000 members in 55 local branches as well as 500 national members throughout Scotland. Around a third of our members have a learning disability. ENABLE Scotland campaigns to improve the lives of people who have learning disabilities and their families and carers.

Many people who have learning disabilities in Scotland rely on the support of Disability Living Allowance to meet the additional cost of living with their disability. Disability Living Allowance is also vital to their independence and assists them with their daily lives.

We recently responded to the following public consultations:

- In October 2010 on 21st Century Welfare¹
- In February 2011 on Disability Living Allowance reform²
- In August 2011 on the Initial Draft Assessment Criteria of Personal Independence Payment³

This response has been prepared following consultation with our members, staff and people who have learning disabilities. The views of our membership were captured through discussion with our members, our Inclusion group and our Practice and Participation team.

Responses to Consultation Questions

The need for DLA reform

How well understood DLA is

Disability Living Allowance (DLA) is well understood amongst people who have learning disabilities as being a benefit which is available to them in order to cover the additional costs of their disability. Disability Living Allowance is also well understood by parents and carers.

However, we believe that DLA is not so well understood by the media and the general public. Much of the Government’s rhetoric in the initial draft budget encouraged a popular belief that Disability Living Allowance is a work-related benefit.

We believe that the Government needs to be very clear and explicit to the DWP that DLA is not work-related and we would ask that staff administering the scheme receive training on this. We would further ask that information on this is provided in a variety of formats so that those who receive DLA understand that this benefit is not dependant on their employment status.

Why the DLA caseload and expenditure has increased

It is undeniable that both caseload and expenditure on DLA has grown since its inception as a benefit to cover the additional costs faced by disabled people. In their original consultation document on DLA reform, the Government referred to a 30% rise in Disability Living Allowance claimants since 1992\(^4\). However, there are a number of reasons for this growth. These include:

- When DLA was introduced in 1992, disabled people aged over 65 were not able to apply for it, instead they were able to apply for Attendance Allowance. However, DLA continues to be paid to people who have gone over the age of 65 since they started receiving DLA provided that they continue to satisfy the conditions of entitlement. The Government’s own statistics say that this accounts for a growth of 6% of the overall 29% of growth in DLA claims since 1992/93\(^5\).

- According to the Government’s own statistics 7% of the overall 29% of growth in DLA claims since 1992/93 is to the UK’s population growth between 1992 and 2011\(^6\).

16% of the overall growth of DLA claimants remains unexplained. Across, the UK there have been significant demographic changes since 1992. Medical advances and better understanding of disability has meant that disabled

\(^4\) http://www.dwp.gov.uk/docs/dla-reform-consultation.pdf
\(^6\) Ibid.
people are more likely to live longer and there is a growing disabled population. This is undoubtedly something that we should celebrate as a society, despite any financial issues it may raise. It is also the case that severely disabled children are not more likely to survive into adulthood as a result of advances in medical science.

Other explanations could be better knowledge and communication of the availability of Disability Living Allowance to cover the additional costs disabled people face.

The Government seems prepared to accept that our ageing population should be planned for, however, it does not seem willing to accept that a growing older population means that there will be an increasing number of people who lack a level of independence and have significant levels of additional costs associated with this.

The growing number of disabled people claiming Disability Living Allowance has been described as “inexplicable” by some sections of the media7. We hope that now they have been explained, the Government will communicate this information more widely.

The effectiveness of the decision-making and review process for DLA

The Government has stated its commitment to ensuring that the new system will be “simple for the claimant to claim”8. We agree that this aspect of the current decision-making and review process for Disability Living Allowance may need reform. One aspect is the long and complex application system which has been created. In 2005, 97% of disabled people responding to a survey about Disability Living Allowance said that the form was “difficult to complete”9.

However, the proposed medical assessment process for the Personal Independence Payment (PIP) will only lead to further complexities. In our experience, many people who have learning disabilities find medical assessments harrowing and often they do not understand what is being asked of them. Parents and carers also tell us of the emotional strain of going through the current application process once – continual reassessment will increase this anxiety.

Implications of a reduction in expenditure:

The implications of focusing on those with the greatest needs

The initial paper on Disability Living Allowance reform10 stated the Government’s intention to “ensure that resources are focused on those with

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8 http://www.dwp.gov.uk/docs/pip-briefing-delivery.pdf
the greatest need.” However, the Government has still failed to qualify or
define who is at “the greatest need”. We are concerned that many people
who would be classified as being at a “lesser need” will not receive the
support they require to meet the additional costs associated with their
disability.

A sole focus on those disabled people with “the greatest need” may exclude
many disabled people who will still face considerable additional costs as a
result of their disability. Meeting these needs has preventative benefits as
well as providing important support.

People who have lesser needs are disproportionately affected by cuts to
social care and welfare reform in general. This could lead to unsustainable
pressure on social care or NHS budgets and, in the context of the current
financial difficulties being faced by local authorities and health boards, this
could mean that many people’s needs will be unmet.

**The likely impact of having only two rates of PIP in the ‘daily living’
component**

The Government has still to clarify how this will affect people who currently
claim the middle and low rates of the “care” component of Disability Living
Allowance. Many disabled people are concerned that the removal of one rate
will mean that those on the middle rate will move to the low rate and those
who are on the low rate with lose their right to this benefit.

We believe that the Government must clarify this situation to prevent any
further, unnecessary anxiety amongst disabled people.

**The number of current DLA recipients who would not be eligible for PIP.**

The Government’s initial policy briefing suggested a 20% reduction in
expenditure and caseload¹¹. This has been amended and now the 20%
reduction just relates to expenditure. As a result it is now unclear how many
people will lose this benefit as a result of such a reduction in expenditure.

It also remains unclear how the 20% figure was established. Whilst the
moves towards reform may be necessary, its drivers appear to be an attempt
to meet a financial end, rather than achieving a better system and better lives
for disabled people.

**Funding overlaps**

The extent to which overlaps in funding exist, particularly with local
authority and NHS funding, and including for people in residential care
or hospital.

¹¹ [http://www.hm-treasury.gov.uk/d/junebudget_costings.pdf](http://www.hm-treasury.gov.uk/d/junebudget_costings.pdf)
We are concerned that the potential removal of the mobility component of DLA from 80,000 people in residential care will undermine the realisation of the Government’s ambitions to promote social justice for disabled people. The mobility component helps people in residential care to pay for things like accessible transport or mobility aids such as an electric wheelchair. In some care homes this money is pooled and used to buy or lease a car which staff can use to take people out into the community.

We believe that the assumption behind these proposals is wrong and is based on a misunderstanding that people living in residential care have all their needs met by local authorities or that they never need to leave the home. The mobility component of DLA, on top of a local authority care package, can help disabled people in residential care to play an active role in their community and encourage independence and relationships with friends and family.

**Automatic entitlements**

Whether automatic entitlement should apply to people with some conditions or impairments and whether some people should receive awards for indefinite periods.

Whilst we understand the rationale for proposing a regular reassessment of DLA claimants, for many people who have learning disabilities a regular reassessment will be inappropriate and costly. Learning disability is a lifelong condition – people are born with it and will have it all of their life. We believe regularly reassessing individuals whose disability and level of independence is unlikely to improve is counterproductive and will create additional cost to the system rather making financial savings. It would also create needless stress and anxiety for the individual concerned and their family carers.

We call on the Government to withdraw the requirement to carry out a continual assessment for people who have lifelong conditions and propose a similar approach to Employment and Support Allowance is adopted – creating separate groups of claimants depending on whether or not a reassessment is necessary.

**Qualifying period**

The implications of a six month qualifying period.

We are concerned that the financial implications of this change will be significant for people who have learning disabilities and their families. The additional burden of having to wait six months for financial support, to which they are entitled, will force many families further into poverty.

Additionally, many people who have learning disabilities also acquire additional physical impairments, sensory impairments or other disabilities over their lives. An increased qualifying period could lead to many disabled people

being forced further into debt to deal with the extra costs of another impairment that will challenge their independence. We believe that the Government should review this change.

**Passporting**

The extent to which PIP will act as a gateway to other benefits, including Carers Allowance and the Motability Scheme.

We are particularly concerned about the impact on carers of the removal or reduction in disabled people’s benefits. Many carers will be affected, as they will lose eligibility to Carer’s Allowance if the person they care for no longer gets DLA. This could undermine unpaid care by making caring financially untenable for many families and could cause an increase in the number of disabled people having to go into residential care – with financial implications for state services.

At present DLA acts as an effective gateway to other types of help – for instance the National Concessionary Travel Scheme in Scotland is available to people who qualify for the high rate mobility component of Disability Living Allowance.

Its removal would result in a higher administrative burden on such schemes and increased anxiety for people who have learning disabilities and their parents and carers.

**The design of the PIP assessment**

**The assessment criteria and design**

Our response to the Department of Work and Pension’s consultation on the Initial Draft Assessment Criteria of Personal Independence Payment goes into more detail on our thoughts on the criteria and design of the PIP assessment. Some of our main points include:

- Too heavy a focus on the medical model of disability, when there are many social barriers that are significant factors affecting the independence of disabled people

- The criteria only focuses on the basic things in life that we all need to get by. It is our view that there are many other factors related to independent living which are not clarified within the criteria. This includes access to things like personal assistance, accessible information, education, employment and housing

- “Continual prompting” and “continual assistance” are very high thresholds and may not be reflective of the type of support that people who have a learning disability require
• Weighting is set at the “low” rate for the “Managing medication and monitoring health conditions” activity. It is vital to an individual’s continual wellbeing that they are able to receive the correct medication at the right time.

We believe that, in their current form, the criteria for assessment will require significant amendments if they are to be suitable to accurately assess disabled people’s level of independence.

**Whether the assessment can objectively assess those with mental, intellectual and cognitive conditions and with fluctuating conditions**

Whilst a learning disability is a lifelong condition which is unlikely to change over time, impairments such as autism and Asperger’s can fluctuate significantly over time. This can be put down to a range of factors, including: anxiety levels, the weather, the time of year or the environmental surroundings (e.g. noise levels, crowded rooms, brightness etc.). Many people on the autistic spectrum also experience difficulties with anxiety and depression, which are themselves also fluctuating conditions.

Such conditions can lead to the individual experiencing both “good days” and “bad days”. We are concerned that this assessment process will not necessarily accurately represent the impact of a disability on someone’s independence if they are assessed on a “good day”. Equally, any failure to take account of non-medical preventative factors and support measures could give a misleading reflection of the impact of a person’s impairment on their level of independence.

**The extent to which aids and appliances should be taken into account in the assessment.**

There is a lot of innovative work currently going on with regards to the aids and adaptations used by people who have learning disabilities. In particular travel aids, such as Satellite Navigation systems, are being trialled as methods of helping people to travel.

We believe that the initial assessment process should take account of aids and adaptations used by the individual at the time. However, we do not believe that this should include any aids or adaptations that they “could use” as was intimated in the initial DLA reform document. Many people are unsure of which aids and adaptations will be beneficial to them.

However, we would still urge caution as it is difficult to envisage any aids and adaptations reducing the costs of learning disabilities. One particular concern we have is that the Government may use telecare as an example of such an aid or adaptation. We believe that whilst telecare can have an important role to play, it does not reduce the cost of living with a learning disability.

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The delivery of the PIP assessment

Who should carry it out

We believe that in order to have a balanced and fair assessment process, this should be handled by independent specialists. Proposals to sub-contract assessments to organisations with a financial incentive placed on removing people from the benefit, as happens with the Work Capability Assessment, are not appropriate if the real reason for reform of Disability Living Allowance is to recognise the people who have the greatest barriers to their independence. ENABLE Scotland believes that if the veracity of the assessment process is to be trusted by disabled people, assessments must be carried out by professionals who are independent.

The approach to tendering for the assessment contract; who should make the award decisions

No comments

Whether there are lessons to be learned from the Harrington Review of the Work Capability Assessment

ENABLE Scotland believes that the Government must learn from the experience of the implementation of the Work Capability Assessment. The Government must ensure that this learning is used to build the assessment process for the Personal Independence Payment.

The technical note that supplements the Initial Draft Assessment Criteria for the Personal Independence Payment identifies “trained independent assessors” who will “provide advice to a departmental decision maker” and have a “face to face consultation” with each disabled person. Our members have told us of examples where the assessment was carried out as a “tick box exercise” with little interaction between the assessor and the person being assessed. It is of the upmost importance that every assessor has the necessary skills and experience to make true judgements about people who have learning disabilities. It is also vital that every assessor understands the diverse range of communication techniques that are used by people who have learning disabilities.

Additionally, there is evidence of people who have not been allowed to take a supporter into the assessment with them or advocates not being allowed to say anything or participate in the assessment in anyway. Some people with learning disabilities will have difficulty in expressing themselves and may be unused to a face to face assessment process which could inhibit their behaviour. Supporters and advocates will put forward the individual’s point of view.

It is common for people who have learning disabilities to portray themselves as being more independent than they actually are. People who have learning disabilities often wish to please questions and give them the answer they want
to hear. This often results in them exaggerating their abilities and skills. In a face to face interview this will work against people who have learning disabilities and give an inaccurate reflection of their level of independence. Advocacy and appropriate representation will help address this, giving a more accurate picture of a person’s capabilities, reducing the number of appeals and more importantly stopping people from being incorrectly assessed as not requiring the Personal Independence Payment.

ENABLE Scotland believes that removing supporters or advocates from this process risks an inaccurate assessment and is completely unacceptable. We believe that this action may risk breaching provisions under the Adults With Incapacity (Scotland) Act which allow other people to intervene in an adult’s affairs if that adult is unable to take decisions or manage their own affairs.

Interaction with other eligibility assessments.

No comments

Children and older people

How DLA/PIP should apply to children and people over the state pension age

While it is true that a child’s needs change as they grow older, it should be stressed that a child who has a learning disability will grow into an adult who has a learning disability. As such, they will always require additional support and financial help to meet the considerable extra costs to the family (see answer to Question 3 above).

Any assessment should be carried out sensitively and with the full participation of parents and/or carers. Parents’ views must be taken into account, as they know their child better than anyone else. Also, in line with Article 12 of the United Nations Convention on the Rights of the Child, wherever possible, a child should be allowed to have a say in decisions which affect them, and their views listened to.

Assessments should be carried out by healthcare professionals with a knowledge of learning disability and they should also be known to the child, for example their GP. Meeting a stranger under such stressful circumstances could potentially be very distressing to a child who has learning disabilities and may have an adverse impact which lasts beyond the day of the assessment.

If children are undergoing assessments for other purposes e.g. at school in order to determine what additional support they require, the information in this could be shared with PIP decision-makers. There seems little point in duplicating this work, not to mention causing undue and unnecessary stress to families in attending numerous, intrusive assessments. Sharing information in an appropriate and sensitive manner is at the heart of the Getting it Right
for Every Child approach which underpins many of the Scottish Government’s policies relating to children.

Paragraph 40 of the consultation questions (on DLA reform 2011) “whether or not we should take into account a child’s support needs if they are being met from public funds by another institution, such as a school”. If the implication here is that PIP would not be paid to a family with a disabled child under these circumstances, ENABLE Scotland would strongly object to this proposal. Families with disabled children have many extra financial costs to meet other than those at school. The support needs of a child are not limited to educational needs but could extend to all areas of their life. Not awarding PIP to a disabled child on this basis would have a detrimental effect on the quality of life of the child and their family and may even limit their ability to meet the basic costs of living.

**Communication**

The steps DWP needs to take to ensure that its reform proposals are clearly and effectively communicated to claimants and the general public.

We believe that it would be helpful for the Government to carry out a high profile media campaign explaining that PIP is to help disabled people meet the extra costs incurred by their disability, in order to counter some of the negative misconceptions which have been fostered within the media.

Information about where disabled people can find assistance to fill in the claim form would also be very helpful, for example local Carers’ Centres, local authority Welfare Rights Teams and Citizens Advice Bureaux.

**Transition**

**Transitional arrangements**

No comments.
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 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, 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, Minister for Disabled People Maria Miller 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 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

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1 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.
3 http://www.publications.parliament.uk/pa/cm201011/cmhansrd/cm110310/text/110310w0003.htm #11031072001181
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 for the Call for Evidence.

7. **About autism**
   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.\(^4\) 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 just 15% are in full-time employment.\(^5\)

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\(^6\):

   - 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

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\(^5\) Based on a working age population of approximately 37 million people and a prevalence rate of 1 in 100.

\(^6\) 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/%20Exist%20-%20the%20message%20from%20adults%20with%20autism.ashx](http://www.autism.org.uk/~media/NAS/Documents/About-autism/Autism-library/Magazines-articles-and-reports/Reports/Our-reports/%20Exist%20-%20the%20message%20from%20adults%20with%20autism.ashx)
• 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 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 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

15. Assessment criteria

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 (attached in Appendix 1) covers all NAS’ concerns, but below is an outline of our main concerns.

18. **Draft assessment criteria**

   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 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
element 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 7
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.

36. **Delivery of the assessment**
   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 paper8 from last year found, there

8 DWP Report 649: The impact of Disability Living Allowance and Attendance Allowance: by Anne Corden, Roy Sainsbury, Annie Irvine and Sue Clarke
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.

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.
Written evidence submitted by Danka Gordon (PIP 44)

Summary

This submission accepts the need for some reform to DLA, but questions the rationale for abolishing it. The social model of disability, which is used by DWP to underpin the proposed PIP assessment, is problematic in ignoring the reality of the impact of impairments on disabled people’s lives. It is argued that the reduction in expenditure will mean that many people whose lives are negatively impacted upon by their disability will be less able to engage in society as a result of losing both the financial support of this benefit, as well as other services to which the benefit passports. Taking the use of aids into account during assessment to indicate a lack of impairment demonstrates a lack of understanding of both the purpose of aids and the reality of impairment and disability.

It is argued that the government/DWP have had a hugely damaging impact on the reputation of people with disabilities and an associated negative effect on society’s attitudes generally toward disabled people. Considerable work must be undertaken to counteract this if disabled people are to have any confidence or trust in the DWP and any changes to DLA.

1. The need for DLA reform

I have absolutely no problem with the idea of reforming aspects of DLA in order to improve it. However, the fact that the reform is linked with cutting the amount spent on DLA by reducing the number of people entitled to it, suggests the underlying motivation is less praise-worthy.

a) It is claimed that the DLA assessment is too long and complicated. The danger with seeking an assessment that is shorter and less complicated is that it will also be less accurate and meaningful. The fact that there may be increased reliability between assessors is not sufficient to make it more valid, i.e. resulting in a meaningful assessment that adequately captures the impact of an individual’s disability and impairment on their functioning.

Somewhat ironically, it is stated that one of the rationales for this reform concerns public perceptions of widespread fraud amongst DLA claimants. This is largely mediated by government expressed opinions and media bias. The current DLA Assessment is a rigorous, time consuming, highly stressful procedure. Yet the government has repeatedly suggested it is given without proper assessment - it seems as if you just have to ask to get it. The implication is that recipients are generally undeserving and have been receiving DLA on false pretences.

b) It seems to me that any current shortcomings of DLA could be addressed far more appropriately and cheaply than the whole-scale reform that the introduction of PIP involves (which itself will come from the budget, which would be better spend on
offsetting the additional expenses living with a disability involves). It would also be significantly more humane than continuing with these attacks on vulnerable people.

It has always seemed to me that it is MPs and the media who have the most problems understanding DLA, rather than disabled people. Perhaps this is because disabled people understand the impact their disability has on their life and costs of living and hence the rationale for DLA.

2. Implications of reduction in expenditure

a) The implication of only those with the “greatest need” receiving PIP is that those with lesser needs neither merit nor need its support. This then suggests that those on DLA who will be excluded from PIP have been undeserving of a disability benefit.

Raising the threshold by which disabled people are deemed to be entitled to PIP will reduce the number of people eligible and hence the total costs in benefit payment. However, this does not change excluded people’s impairment and needs. What will be achieved is the creation of a group of people who will be unable to engage in society as fully due to lack of money to fund the additional costs caused by/related to their disability. Moreover, the ability to pay for the basic needs of everyday life, such as extra heating, aids to help impairments will be gone. This may result in deterioration in some people’s condition. Ironically, if they then qualify for PIP, there would a real disincentive to report any consequent improvement.

b) I think there is a clear rationale why DLA mobility has two rates and care three. There is a huge gap between the needs of higher and lower rate care recipients. I am on the middle rate care. There is no way that I would (or should) qualify for higher rate care and yet my care needs are significantly more than the lower rate criteria. I believe changing to two levels is designed merely to exclude those with lower care needs. And, of course, some people will be deemed to no longer have care needs, irrespective of how their disability impacts on their ability to care for themselves. So, cutting expenditure will be achieved, but the cost to the disabled person will be notable.

c) I have no idea whether or not I will qualify for this proposed new benefit. People who know me think my concern unjustified. Nevertheless the underlying message that not everyone on DLA merits it means that on a personal level I feel continually devalued by the society in which I live and increasingly stressed by being demonised as a “scrounger”. Thus the proposed reform of DLA becomes part of the continual attacks on the integrity of disabled people who claim disability benefits. Increasingly negative attitudes toward disabled people by wider society are bolstered by this. Perhaps it is no surprise that hate crime and attacks on disabled people are increasing.

While the government has stated that the purpose of PIP will remain the same as that of DLA, by focussing on expenditure and relative need, rather than actual functional need, this benefit will, by definition, no longer be able to meet its prime objective.
3. **Automatic entitlement/length of award**

It is argued that people do not know when or how to report changes in/to their situation. It has always seemed reasonably clear to me. The effect of having being awarded DLA indefinitely has helped to provide an element of security in a very uncertain, stressful life. In any event, surely it would make more sense to develop new, more specific reporting systems, rather than abolishing the whole system. For instance, for people like me, who have a chronic and slowly deteriorating condition, with virtually no likelihood of significant improvement, it would be simple to send an annual statement to sign to confirm that no significant change had occurred – of course it would specify in detail what is being asked, with relevant examples. More detailed questionnaires could be used, perhaps, at five yearly intervals. Denying the use of indefinite awards for the majority of people who currently receive them and then repeatedly subjecting them to assessments, seems to me to be an unnecessary cruel and punishing process. Repeated assessments, particularly face to face, merely serve to humiliate and stress. It feels as if you constantly have to justify your existence and prove how inadequate you are. No reframing by focussing on what I can do stops the highlighting of what I cannot do.

4. **PIP as a gateway**

DLA as a gateway has worked very well for me, providing a useful indicator to organisations that the recipient has a valid need for their service/subsidy/special access. The converse is of great concern; disabled people, who are assessed as having “lesser need” will then also lose access to crucial other benefits and support. Given that operating PIP with a reduction in expenditure means excluding approximately 20% of current DLA recipients, the result of this will be to deny these people associated benefits that offset both physical and financial barriers to maximise functioning in society.

In addition to the benefits you mention, the loss of the blue disabled parking badge could have a dramatic effect for many disabled people. There are a huge number of places that I would be unable to visit without my blue badge, including G.P., hospital, dentist, shops, art galleries, and attractions. Some places offer a free ticket when I need a companion to enable me to access their facility. Similarly, access to community and health and social services is mediated by being in receipt of disability living allowance, as evidence of one’s disability.

5. **Design of PIP assessment**

a) There is a fundamental problem in using the social model of disability as both the underlying philosophy and basis of the assessment for PIP, which the government argues it is doing. The social model does not comprehensively encapsulate the reality of living with a disability/impairment in our society; it describes one aspect, but excludes consideration of the impact of the impairment itself. (Tom Shakespeare’s excellent exposition of these arguments should be referred to for full details; Shakespeare, T., 2006, Disability Rights and Wrongs, Routledge).
It is a misunderstanding of the reality of disability and the social model that leads to the proposal to take the use of (hypothetical or real) aids and appliances as obviating the effects of disability. Aids are just that – they help; they do not remove impairments. To base an assessment on the assumption that aids mean someone no longer has an impairment is absurd. It demonstrates the lack of understanding of the reality of living with disabilities by the proponents of this reform. Walking sticks and wheelchairs may/do help, but do not remove mobility problems and associated effects. For example, I have major mobility problems, each step I take causes pain and I can only manage a few steps at a time very slowly with a stick. However, sitting aggravates my spine condition; a wheelchair does not solve my mobility problem.

b) The NHS provides some mobility aids, but these are of a very basic type for most people. For example the manual wheelchair I was provided with was too heavy for me and injured my shoulders, which now cause additional problems. But as I am not a full-time wheelchair user (I do not use it in the home), I am entitled to neither a light manual chair nor a powerchair.

If having mobility equipment means my mobility impairment is ignored, how am I supposed to fund them? I have used my DLA payments to help fund my 80% contribution to a wheelchair that meets my clinical needs. Moreover, walking sticks and wheelchairs wear out, need maintenance and insurance. All mobility related equipment is very expensive.

c) I am considering getting a powerchair. However, I am conscious that it may mean my mobility problems would be deemed non-existent, even though they would still exist. I have to think of the implications of this in my decision-making. I suspect many people will be similarly put off funding aids that could help. This is self-defeating, of course, and highlights the importance this benefit has for easing some of the difficulties of disabled peoples’ lives.

d) The idea of taking a theoretical aid into account is patently ridiculous! How would it be funded? Who would provide it? Certainly not the NHS. Further, it highlights the lack of understanding about using aids such a wheelchair. Prior to having my first wheelchair, I assumed (theoretically) that when I got it, it would significantly improve my ability to mobilise. The reality is VERY different.

e) It is being claimed that anti-discrimination legislation means that social barriers need no longer be considered. This is disingenuous. While such legislation may lessen the problems of disabled people, they have not removed all barriers and never could do so. Not all public transport is accessible; not all buildings are accessible; attitude change needs time and cannot be achieved purely by legislations (moreover, as mentioned, government expressed attitudes to disabled people, focussing on us as benefits cheats, do not foster positive attitude change).
f) Regarding activities excluded from the assessment. There continues to be an assumption that most disabled people will be living with an able-bodied person, thus discriminating against people, like me, who live alone and also those living with other disabled people. This is clear because absolutely no attention is given to key essential daily activities related to domestic chores, which for many people with physical disabilities cause huge problems/are impossible/require higher costs than for the able-bodied – paying for help/more expensive equipment etc. I urge that such essential domestic chores be recognised as a fundamental activity of daily life that must be assessed in any revision to DLA.

g) When assessing people’s ability to carry out specific tasks, it is important to take into account real life situations, rather than in ideal conditions. Very little in life runs smoothly in terms of the reality of getting somewhere, cooking, personal care, domestic tasks. For example, transport does not run on time, traffic jams are a daily feature of life in a city, parking bays are suspended. The minor inconveniences of everyday life become major barriers when impairments exist. Assessing capacity to do things and mobilise etc. in optimal conditions is rarely an accurate reflection of life.

When assessing people’s mobility this needs to be in the real world. The proposed assessment looks at the ability to use a wheelchair on flat ground. Life isn’t a level playing field in more ways than one! Pavements have cambers, bumps and obstacles even the smallest incline feels huge to me in a wheelchair, ramps tend to be very steep, there are small steps everywhere. Hence, considering an ability to walk/use a wheelchair on a flat surface is meaningless in the real world, as well as demonstrating a complete lack of knowledge/understanding of what is the reality of using a wheelchair. Perhaps they should all spend a week full time in a manual wheelchair?

h) The DWP keep emphasising the importance of focussing on what people can do, rather than what they cannot do. In a job interview emphasising and focusing on what someone can do is essential. However, in an assessment of the impact that someone’s disability/impairment has on their life merely emphasising what can be done will always give an inaccurate and distorted picture. If you have a long-standing disability that has a negative impact on your life, one of the most helpful ways of managing is to downplay and minimise its effects when talking to others. This helpful way of surviving life with a disability is not a helpful strategy when being assessed by a benefits assessor. A professional who knows the true nature of your problems and its impact on your life is far better placed to make a valid and reliable assessment and it is essential that due weight is given to their report. The consultation document talks about “considering information” from other professions; this is very different from recognising their expert knowledge of the claimant and taking advice from them.

6. Delivery of PIP assessment

Perhaps the government need to reconsider how appropriate it is to outsource work related to welfare to a private company, which is inevitably governed by the profit motive. I do not believe that delivery of the assessment by “independent healthcare
professionals” employed by such a private company is ever going to be considered trustworthy by the people they assess. Experience with ATOS does not suggest otherwise.

ATOS has a dreadful reputation amongst disabled people as a result of their current assessments for DWP. The number of their decisions that are overturned on appeal does not engender confidence. Given a clearly stated aim of the change to PIP is to reduce the number of people who qualify for it, any private company employed for the assessments will be under pressure to reduce the numbers who qualify in order to keep their contract. This inevitably questions the independence of an assessment conducted by professionals they employ. There are currently no sanctions imposed for all the poor quality assessments currently being undertaken which are then overturned on appeal. It is not good enough to say that the appeals process safeguards the assessment process and that overturned decisions show it works. This ignores the profound impact on vulnerable individuals of the wrong decision – financial and psychological.

ATOS’ bullying online behaviour does it little credit. Seeking/threatening legal action in order to shut down sites that criticise it should be strongly discouraged by the government. Recently a carers’ forum was shut down by its host due to ATOS legal threats; a site where claimants describe their assessments was similarly shut down as a result of ATOS threats. ATOS undertake many PR initiatives to improve their image, but the above actions, together with the high proportion of inaccurate/poor assessments, will always invalidate these in the eyes of most claimants. I suspect it may be too late for ATOS to ever lose its appalling reputation and undo that damage caused by their attitudes and poor performance.

7. Communication of reform proposals by DWP

First and foremost there need to be public statements/media campaigns by both DWP and the government to counteract the damaging attitudes expressed to date. For example, selectively distributing press releases of the top ten “excuses” given by people found to have made fraudulent claims to right wing tabloids that delight in moral outrage is public manipulation of the worst sort. As long as this type of public attack continues to be made, disabled people will have little, if any confidence or trust in the DWP and government to safeguard our needs. Rather, it just confirms that we are seen as an unvalued, undeserving burden on society, taking public money under false pretences. At a time of austerity disabled people become a soft target for the media and public to cruelly scapegoat. Many of us are unable to stand up for ourselves (both literally and metaphorically). For the government to be providing ammunition for such unfair representation is unforgivable.
1. Summary

1.1 Deafblind people face significant additional costs related to their disability, especially in relation to communication and mobility. Our evidence focuses on the areas of particular concern to deafblind people.

1.2 Reform of DLA should be driven by the needs of disabled people rather than cuts to expenditure.

1.3 The qualifying period for PIP should be 3 months rather than the proposed 6 months.

1.4 The mobility component of PIP should be retained for people living in local authority funded residential care.

1.5 The ‘automatic’ entitlement to the higher rate mobility component should be retained for qualifying deafblind people. Long term and indefinite awards should continue to be used as appropriate.

1.6 The assessment process should look at the practical impact of disability rather than the medical model employed in the current draft of the assessment criteria.

1.7 Due to the lack of understanding of the impact of deafblindness among mainstream healthcare assessors, evidence from individuals, family members and professionals with a specialist understanding of deafblindness must be given higher weight during the assessment process.

1.8 The Welfare Reform Bill should be amended to state on the face of the Bill that people over state pension age are entitled to PIP, where they continue to meet eligibility criteria.

2. Introduction

2.1 With over 50 years of experience, Sense is the leading national charity working with, and campaigning for, children and adults who are deafblind. Sense provides expert advice, support, information and services for deafblind people, their families and professionals.

2.2 Deafblindness is a combination of both sight and hearing difficulties. The complex impact of dual sensory loss means that it is a unique disability. Deafblind people need support with communication, access to information and mobility. Based on independent research, there are an estimated 365,000 deafblind people in the UK.\(^1\) If deafblind people do not receive support with

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\(^1\) Robertson, J., and Emerson, E., Centre for Disability Research, 2010, Estimating the Number of People with Co-occurring Vision and Hearing Impairments in the UK
mobility and communication needs, they can remain trapped in their own homes and cut off from society.

2.3 Deafblind people face both very significant ongoing and one-off additional costs related to their disability. These costs are not met by social care or other services. These additional costs are extremely varied but examples include:

- Paying for interpreters: £25 - £35 per hour;
- Braille display for computer: £3,000 - £7,000;
- Braille notetaker: £4,500+;
- Screen reader software: £500 - £900;
- Screen reader software updates: £200 - £500;
- Braille textphone software: £300+;
- Repair of specialist equipment: up to £2,000;
- Online shopping when it is not possible to go to the shop: £100 per annum.

3. The approach to DLA reform and the implications of a reduction in expenditure

3.1 Whilst there is the potential to improve DLA we do not believe this requires abolishing the benefit. Many of the modifications needed could be achieved through better training for staff and through modernising the criteria used. We are particularly concerned at the overall objective of a ‘reduction target’ of 20% in future spending as set out in the June Budget 2010. Although the Government has stated its commitment to supporting disabled people, we are concerned that the approach being taken is primarily concerned with reducing costs.

3.2 If those who currently receive the lower rate DLA care component are no longer eligible, this will drastically decrease preventative support for disabled people. It will have a significant impact on individuals’ physical and mental wellbeing and increase pressure on health and social care services when unmet low level needs develop into higher needs. Indeed, as the Dilnot Commission on adult social care recently acknowledged, meeting lower level needs is essential to ensure prevention of higher or crisis level needs.2 It should be noted that having three, rather than two, different levels of support can ensure a greater degree of sensitivity to individual circumstances.

4. Six month qualifying period

4.1 We are deeply concerned by the proposal to extend the qualifying period for PIP. We think this will delay support for deafblind people and place additional financial pressures on them.

4.2 The Government states that this will align the qualifying period with the definition of long-term disability in the Equality Act. However, this could be also achieved by retaining the three month qualifying period and extending the period of future need. The Government has also stated that doubling the.

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2 Dilnot Commission (July 2011) Fairer Care Funding, 21
qualifying period for PIP will bring the benefit into line with Attendance Allowance yet there is no prospective test for Attendance Allowance. The two benefits cannot be ‘aligned’ in this way.

5. Overlaps in funding: the mobility component for people living in residential care

5.1 Under Clause 83 of the Bill disabled people living in local authority funded residential care could have their mobility payments taken away. We do not believe it is right to target a specific sub-group of disabled people in this way and this part of the clause should be removed from the Bill.

5.2 The Government’s justification for removing DLA/PIP mobility is to ‘identify and remove any overlaps’ in the way mobility needs in residential care homes are met. However, evidence shows that very little duplication exists, and removal of this benefit would severely undermine the Government’s aim to support disabled people to lead full and independent lives. As pointed out in the reports Don’t limit mobility and DLA mobility: sorting the facts from fiction, while care packages may meet specific needs such as going to a day centre or a doctor’s appointment, they are unlikely to factor in the costs of visiting friends and family and participating in community and leisure activities. Any occasions of inappropriate use of the benefit should be dealt with in a proportionate way, rather than threatening to remove the mobility component from everyone living in local authority funded residential care. Deafblind people living in residential care want to be full and active members of their local communities and maintain relationships with family and friends in just the same way as disabled people not living in residential care and DLA/PIP mobility helps them achieve this.

5.3 At publication of the Welfare Reform Bill, the Government announced its intention to ‘review the support given by DLA against the responsibilities of care homes, and reflect the outcomes from this review in the PIP eligibility criteria for people in residential care homes’. However, the Government has since made clear that this is an internal review, with no terms of reference and its findings will not be published in the public domain; we are concerned about this lack of transparency. We therefore look forward to hearing the findings of the independent Low Review into personal mobility in state-funded residential care as providing a more transparent means of looking at this issue.

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7 Parliamentary Question 52907, 52908, 52926, 52927, 9th May 2011, www.publications.parliament.uk/pa/cm201011/cmhansrd/cm110509/text/110509w0003.htm#1050943001014
6. ‘Automatic entitlements’

6.1 ‘Automatic’ entitlements to higher rate mobility should remain for deafblind people and people with a severe visual impairment. While these entitlements are referred to as ‘automatic’, it is important to stress that deafblind people must submit a significant level of evidence in order to be eligible; it is still a rigorous and certainly not always an easy process for deafblind people to be ‘automatically’ granted this award.

6.2 We are concerned that an assessment by a non-specialist will be inaccurate and clear medical evidence is misinterpreted. Therefore, automatic entitlement based on clear mobility needs is effective, accurate, cost effective and easy for claimants to understand.

6.3 Plans to bring in the new benefit and re-assess all current claimants are estimated to cost £675m. At a time of significant reductions in public expenditure, we do not understand the reasoning behind assessing individuals on a face-to-face basis when they have an obvious need for the mobility component. In addition, having automatic entitlements for some groups does not exclude others with equivalent levels of need receiving the same amount of mobility support.

7. The design of the PIP assessment

7.1 We cannot stress enough the critical importance of the assessment process in ensuring deafblind people genuinely benefit from the introduction of PIP and in meeting ministerial commitments that PIP will take better account of the needs of people with sensory impairments, including their communication needs.

7.2 We are concerned that the first draft criteria focus only on those activities required for the bare essentials of existing and will fail to help disabled people overcome the barriers many face to living independently and participating fully in society. The proposed descriptors seem to address a much narrower range of issues than DLA currently does. Therefore, the Department needs to carry out very significant work to ensure the criteria meet the requirements in the paragraph above.

7.3 Currently the criteria look predominantly at the medical impact of an individual’s impairment rather than how this interacts with society to create barriers to independence. For deafblind people it is the impact of dual sensory impairment rather than the specific medical diagnosis that is fundamental. Indeed, when establishing criteria for the assessment, it is vital to understand how combined sight and hearing impairments limit a person’s ability to adapt to and manage individual sensory impairments, thereby multiplying the effect and leading to a unique disability.

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8 DWP (February 2011) Disability Living Allowance Reform Impact Assessment, 2
7.4 We welcome the Minister for Disabled People’s commitment that communication should be taken into account more as part of the assessment for PIP. We do believe that the Government could have investigated more thoroughly that there could be a third communication component for PIP alongside the daily living and mobility components. However, we very cautiously welcome that the technical note identifies ‘communicating with others’, ‘planning and following a journey’ and ‘getting around’ as areas that would score highly under the assessment. However we have grave concerns about the current wording of the descriptors and their failure to live up to the Minister’s commitment to better address communication needs. It is still unclear if the weighting of the criteria will mean that the needs of deafblind people will be adequately recognised.

7.5 We recommend that the assessment is subject to rigorous analysis, such as a Rasch analysis, to ensure that any double-counting or disproportionate weighting for particular impairment groups is avoided. People who face barriers around mobility and communication must not be unduly disadvantaged when compared with those whose needs primarily relate to personal care. While the first draft of the criteria indicates that these two areas would be more heavily weighted, the disproportionate focus of the other descriptors on personal care and other similar tasks seems likely to undo this.

7.6 We are concerned about the definition of ‘intermittent’ as meaning ‘the physical presence and physical intervention…at least half the duration of the activity’ and how this will be interpreted in relation to the support that some deafblind people need. While some deafblind people require support with activities for half the time or more, some would need support at equally crucial but less frequent intervals. For example, someone may be able to follow a journey more independently, but require assistance with pedestrian crossings, hazards or unpredictable incidents. We therefore believe that ‘intermittent’ should be defined as only requiring the presence of someone for at least half the duration of the activity rather than being tied to a particular level of intervention during that period.

8. Assessment by an ‘independent healthcare professional’

8.1 Mainstream healthcare professionals have very limited knowledge of the impact of dual sensory impairment on daily living. Indeed a small group of deafblind people have been involved in the department’s piloting of the draft PIP criteria; their experiences thus far have been very mixed:

“The assessor was a paramedic and made a good effort to understand deafblindness. He did not follow the form and we talked about the day in the life of R, then he [the assessor] fit relevant information into the correct parts of the form. He made the form fit R.” (Parent of a deafblind young man)

“I felt that the assessment interview was more about my physical and not my sensory abilities. For example, I was asked to lift my arms as high as I can. I was asked to grip the person’s hand as hard as possible. But there was no test about sight, or hearing.” (Deafblind man)
“He didn’t really get dual sensory loss, more physical impairments. He asked questions about getting to the bathroom and toilet, which is not a problem. The assessor stuck to the form rigidly...He had never heard of Usher syndrome and made no efforts to ask questions to find out more or to seek clarification.” (Deafblind man)

8.2 It is therefore essential that some level of training and information on deafblindness is given to the independent assessors. Also evidence given by individuals, family members and professionals with a specialist understanding of deafblindness must be given a higher weight by Decision Makers.

8.3 It will be essential to allow for adequate time given to submit and take account of evidence submitted by relevant specialists. Social care specialists in deafblindness will also be key contacts for evidence gathering on the impact of deafblindness. Only then will the Decision Maker be able to make the most informed decision and avoid allocating the wrong awards and placing unnecessary pressure on the reconsideration and appeals process.

8.4 The role of the Decision Maker will be crucial in ensuring that PIP is received by those who need it and in avoiding unnecessary stress for individuals and appeals. Poor decision-making is in itself undesirable, but it also tends to generate large numbers of appeals, a high proportion of which will be successful - again, an unproductive use of administrative resources.

9. Aids and appliances

9.1 We cautiously welcome a commitment to award some points to individuals who can complete activities only with the assistance of an aid or appliance. We hope that this is in recognition of both the additional costs resulting from purchasing, maintaining and replacing them but also recognition that aids and adaptations are only part of the support deafblind people need to be able to participate in society. The successful use of aids and adaptations can also depend on environmental factors: a street environment without sufficient marking and curbs will limit the usefulness of a long cane or very noisy environments will mean some people will need to turn their hearing aid off. Also in some cases aids may bring some challenges for users, for example hearing aids that may improve someone’s ability to hear but could also amplify tinnitus which can have a profound impact on an individual’s ability to complete activities and get around.

10. The review process

10.1 Any review process must be sensitive to the fact that deafblind people’s sensory impairments will either be stable or increasing. In other contexts, deafblind people can be asked if they ‘have got better’ which is both highly distressing and ignorant. Given this situation, any review process must be proportionate to the likelihood of changed needs. For example, a deafblind person who receives the higher rate of either of the components is highly likely to remain in need of those given the ongoing barriers a deafblind person faces. In addition to this many deafblind people have a deteriorating condition, such
as Usher Syndrome, so their needs are only likely to increase. We therefore do not see a case for reviewing their award with a face to face assessment.

11. The delivery of the PIP assessment

11.1 If the Government increases the number of face-to-face assessments for deafblind people, it will be essential to ensure assessors and decision makers fully understand the impact of deafblindness. It will be vital to give due weight to evidence from medical and social care specialists in deafblindness. If this is not implemented correctly, there will be a significant number of unnecessary and costly appeals. Any face-to-face assessment must be accessible to deafblind people. The right kind of mobility and communication support must be provided to minimise stress for individuals and prevent wasted resources.

11.2 Again the piloting of assessment with deafblind people indicates that there have been some significant shortfalls in meeting the needs of deafblind people. This has included inadequate notice given to volunteers, especially when communication support needed to be booked and difficulty obtaining the written information pack in an accessible format. This is particularly disappointing as we had ensured that the Department and G4S were aware of individuals’ access needs at the start of the testing process.

12. DLA/PIP for children and people over state pension age

12.1 Given the specific needs of disabled children, we welcome the Government’s commitment to consult before extending PIP to children under 16 and look forward to further information on how this will take place.

12.2 The Government has indicated that when claimants continue to meet eligibility criteria, they will continue to receive PIP once they are over pension age. Individuals will continue to face barriers over this age and the PIP mobility component is especially vital to people over pension age, given that Attendance Allowance has no equivalent mobility component. Given the Government’s commitment on this issue, we feel it would be appropriate to include this on the face of the Bill, rather than in Regulations.

13. Communicating reform to claimants and the public

13.1 Clear, plain English forms and information should be provided in individuals’ preferred formats (for example large print, Braille, audio, electronic format or different coloured paper). Help should also be proactively offered by the Department and its partners to those who have difficulty in filling in forms because of their disability. Publicity around the introduction of PIP should also seek to counter myths that the benefit is an out-of-work benefit only or that it is means-tested.

14. Transitional arrangements

14.1 We welcome any commitment to ensuring that individuals moving over from DLA to PIP are not any worse off financially. However this must does not
distract from the fact that new claimants may well not be entitled to as much as they would have been if claiming under the current system. We are very concerned that lower amounts for PIP awards will have a negative impact on future claimants and indeed current claimants once transitional protection is no longer relevant due to increments in rates.
1. About Contact a Family
1.1 Contact a Family is the only UK-wide charity providing practical and emotional support and information to families with disabled children – regardless of disability or health condition. We deliver this through local, regional and national offices plus family workers and volunteer parent representatives. We enable parents to get in contact with other families through a family linking service, our network of parent support groups and online resources. We have pioneered the development of parent participation.

1.2 Our freephone helpline offers advice to families on any aspect of caring for a disabled child including community care issues, education needs, and welfare benefits. Our response is based on the expertise of our specialist welfare rights team who speak to parents regarding Disability Living Allowance (DLA) issues on a daily basis. Last year our helpline provided advice to 10,000 families with disabled children.

2. Families with disabled children and DLA

2.1 Many families with disabled children live close to or below the poverty line. It costs on average three times more to raise a disabled child than a non-disabled child. Many parents have reduced earnings because they find it difficult to combine paid work and caring.

2.2 Disability Living Allowance plays an essential role in helping to mitigate some of the financial pressures that families with a disabled child commonly face. It provides a pool of income that a family can use to meet a whole range of disability related costs and acts as a gateway to a range of other forms of financial help for disabled children including additional tax credit payments.

“Without DLA we wouldn’t be able to do the things other families take for granted. I only wish I’d known about it years ago. It wasn’t until another parent told me she was recently help with the additional costs of caring for her disabled children that I found out about DLA. At first I didn’t think I could complete the form but with the help of a family worker from Contact a Family I now get an extra £20 a week” Parent from Bradford

2. Summary
2.1 Contact a Family fully supports the government’s aim of making Disability Living Allowance easier to understand, more transparent and less bureaucratic. However we question the assumption that Disability Living Allowance is no longer fit for the purpose and in need of the scale of reforms proposed.

2.2 Certainly the DLA claim process is cumbersome and complex, with many parents of disabled children complaining about difficulties in completing the claim pack. The Department for Work and Pensions has piloted a new simplified DLA claim form for children and we are currently awaiting details of how and when the

1 Paying to Care: the costs of childhood disability by Barbara Dobson and Sue Middleton
new DLA claim form and guidance for children are going to be rolled out nationally.

2.3 We believe that the introduction of a new, simpler and more efficient claim pack for children would be preferable to replacing DLA for children with a new benefit utilising face to face interviews with health professionals who have never previously met that child. We not only question the appropriateness and efficiency of such a model for children but are also concerned at the likely administrative costs.

2.4 Contact a Family is a leading member of the Every Disabled Children Matter (EDCM) campaign. We fully support the evidence submitted by the campaign to this inquiry which includes our shared concerns regarding:

- Doubling the qualifying period to 6 months
- Adaptations and Aids
- Suspension of DLA mobility in residential accommodation
- PIP and Disabled Young People turning 16

2.5 Research by Contact a Family\(^2\) has shown that many families with a disabled child already struggle financially - almost a quarter are going without heating, more than half have borrowed money from family or friends to keep financially afloat or pay for essentials, and more than a third have fallen behind with repayments on debts such as credit cards. Cuts to DLA will only serve to magnify these problems.

2.6 Despite being among the most vulnerable and often poorest families in society, we estimate that 62% are not claiming Disability Living Allowance, and are missing out on vital extra income. Therefore we would recommend a national benefits take up campaign.

3. The assessment process

3.1 Contact a Family fully supports the government’s aim of making Disability Living Allowance easier to understand, more transparent and less bureaucratic. However we are concerned that assessment model proposed for working age claimants, utilising a face to face interview with a health professional is unlikely to meet these aims for families with disabled children. We believe that developing a streamlined DLA claim pack for children, along the lines of that recently piloted by the Department for Work Pensions, would be a more efficient and cost effective solution.

3.2 In the June 2010 budget statement the government announced that reform of DLA would involve an objective medical assessment based on the Work Capability Assessment (WCA) used in Employment and Support Allowance\(^3\). Contact a Family has a number of concerns about the use of the WCA as a model for assessing the needs of disabled children.

3.3 The WCA is an assessment designed for use with adults of working age and specifically designed to analyse the limitations that may be placed on an individual’s ability to under-take work related activity. It is difficult to envisage how

\(^2\) Counting the Costs 2010, Contact a Family
\(^3\) Budget 2010 Policy Costings, HM Treasury
this model could be applied to assessing the additional needs arising from a child’s disability. It seems clear that the PIP assessment would need to use a completely different set of descriptors from that used in the WCA. However until we have details of what these descriptors would be and what exactly they would seek to measure it is not possible to offer any informed opinion as to the extent that any new assessment could be applicable to children.

3.4 Concerns about an assessment based on the WCA model are also raised by the huge increase in the number of appeals since its introduction. In the last two years there has been a five-fold increase in the number of ESA and incapacity benefit appeals. Department for Work and Pensions figures also suggest that 39% of appeals are successful, a figure that only serves to emphasise limitations of the WCA model. These facts raise questions not only about the appropriateness of using assessments based on an interview with a health professional but also the potential high costs of such a system.

3.5 These worries arise not only from the potential costs of an increase in the number of appeals but also in the costs of the face to face interviews themselves. It seems likely that the costs of administering a replacement for DLA will increase significantly as a result of this feature.

3.6 Some disabled children will have very severe and complex disabilities. Others may have disorders that are so rare that they are poorly understood even by medical practitioners. Disabled children will often already have an array of professionals involved in their care. In such circumstances it is difficult to see how the information gathered by a health professional (who may not have any experience or training in that condition) during a one-off interview would add much to the detailed information about their child’s needs that a parent will provide as part of the claim process, or that will already be held by other professionals involved in the child’s care.

3.7 Similarly we have concerns about how a one-off assessment will accurately capture the overall needs of children whose conditions fluctuate in severity. A ‘snapshot’ assessment of how a child appeared on a particular day may not reflect the complexity of a child’s needs over a longer period of time.

3.8 Ultimately parents are the individuals who have the greatest expertise and knowledge about their child’s condition and how this impacts on their child’s day to day needs. It is crucial that gathering information from the parent remains the central plank of any new assessment process. We favour the use of a new more straightforward DLA claim pack for children to elicit this information. Where there is a need for more ‘objective information’ we believe that it is more appropriate and effective to seek evidence from health professionals already involved in the child’s treatment. Paediatricians and other health professionals already known to the child are in a much better position to provide an assessment than someone meeting a disabled child once for a short period. We believe that making wider use of additional evidence from practitioners already involved in the care of a child would be a more efficient and cost effective way of introducing more objectivity into the process.

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4 Jonathan Djanogly MP in response to written Parliamentary Question, Hansard, 1st Feb 2010
4. Activities to be assessed in determining eligibility
4.1 The government wants to reconsider what is measured in determining whether someone should qualify for benefit payments. It argues that there should be a broader focus on disability than is currently applied in Disability Living Allowance and questions whether care and mobility needs remain the most appropriate proxies for disability related costs.

4.2 There are undoubtedly some areas of DLA eligibility criteria that could be broadened and improved. For instance the rules governing entitlement to the high rate mobility component on the grounds of a severe mental impairment seem unnecessarily complex and restrictive. The current rules require someone to have night time needs as well as day time needs (i.e. qualify for high rate care)\footnote{Section 73 (3) (c) of the Social Security Contributions and Benefits Act}. However the relevance of night-time needs to someone’s ability to get around out of doors is difficult to rationalise.

4.3 Contact a Family would also like to see the criteria for the mobility component amended so that severely disabled children under the age of three are able to qualify if they require to always be accompanied out of doors by bulky equipment or have a condition necessitating quick access to a vehicle. This would bring the rules into line with that of the blue badge scheme in England and Scotland.

5. Reducing the number of rates at which the benefit is paid
5.1 Contact a Family is concerned by the proposal that the PIP component covering help with daily living activities will only have two rates rather than the three rates currently applying to the care component of Disability Living Allowance.

5.2 Currently almost 20,000 disabled children under 16 are in receipt of the low rate care component. Almost 7000 16 and 17 year olds also qualify\footnote{Numbers in receipt of DLA low rate care from DWP Statistical tabulation tool – May 2010 caseload by age of claimant and rate of care component.}. For the families of these children, the loss of the care component could be very damaging. In many cases it would mean not only the loss of £18.95 per week in Disability Living Allowance but also the loss (unless DLA mobility component is also in payment) of up to £52 per week in child tax credit payments. Loss of DLA could also lead to it becoming harder for families to access other services or supports, some of which base entitlement on receipt of DLA.

5.3 If the PIP criteria are more restrictive than current DLA rules, those families with a disabled child who would lose entitlement are likely to face severe financial difficulties. Many families would have no option but to cut back on spending on items such as heating, special dietary needs, therapies not available on the NHS etc. In these circumstances it is not difficult to envisage some children’s conditions worsening, leading to the state incurring higher costs in the future (through increased hospitalisations etc).

5.4 It is unlikely that many families losing DLA would be able to access help with their child’s care needs from alternative sources such as social services. Many families with disabled children already report being refused support by social services departments because their needs are deemed not severe enough. This
is a situation that seems likely to worsen as eligibility criteria are tightened in response to local authority funding difficulties.

5.5 One of the reasons for the introduction of DLA in 1992 was to provide financial help to those disabled people with less severe disabilities whose needs had not been met by the previous system of Attendance Allowance and Mobility Allowance. It is our view that any benefit aimed at helping meet the extra costs faced by families with a disabled child must include support for those whose disabilities may be less severe end of the spectrum but whose family nevertheless face additional disability related costs. We are concerned that this principle appears to be at risk in the design of the new PIP.

6. The end of automatic entitlements for certain groups of claimant
6.1 In our opinion the current system of awarding specific levels of award for a small number of particular conditions such as children who are deaf/blind, those with no legs or feet and from April 2011 children with severe visual impairments, is an efficient use of resources. It is hard to imagine the circumstances where a child with one of the specific conditions covered would fail to qualify for the relevant rate of benefit under a full assessment. As such, automatic entitlement in these circumstances avoids unnecessary administrative costs. Given that administrative costs seem likely to be higher under the assessments envisaged in PIP, we feel that there is a clear argument for retaining automatic entitlements for specific groups.

7. Ending the Motability extension for hospital in-patients
7.1 Contact a Family is also disappointed that the government has proposed ending the current rules which allow a hospital in-patient to continue receiving DLA mobility payments until the end of an existing Motability agreement. This valuable concession allows a family to continue to make use of a car despite the fact that their child has been in hospital for more than 84 days. Many disabled children are patients, not at a local hospital but at a specialist hospital some distance from the family home. The loss of DLA mobility in such circumstances may mean the loss of the family car, making it difficult for some families to visit their hospitalised child as regularly as they would like.

8 The Way Ahead: Benefits for disabled people, HMSO, 1990
9 DWP Business Plan 2011-15, DWP, 2010
Written evidence submitted by South Lanarkshire Council Money Matters Advice Service (PIP 47)

1.1 South Lanarkshire Council Money Matters Advice Service, based within a local authority Social Work service, provides information, advice and representation on welfare rights/social security benefits to the public.

1.2 We work with a wide cross section of the public, many of whom claim Disability Living Allowance.

1.3 We believe we have the necessary expertise to offer the Inquiry a view on the proposed Personal Independence Payment (PIP).

1.4 The following answers some of the questions put forward by the Inquiry.

**Implications of reduction in expenditure/implications of focusing on those with greatest needs/likely impact of having only two rates of PIP in the ‘daily living component’/number of current Disability Living Allowance (DLA) recipients who would not be eligible for PIP.**

2.1 We are opposed to the overriding policy objective of reducing the support available to disabled people by over $2 billion through the introduction of the new PIP assessment. According to figures, PIP will not provide an equivalent level of support for the 652,000 disabled people currently receiving low rate care DLA payments.

2.2 We believe the PIP proposals risk increasing disability poverty by a significant margin.

2.3 We believe the consequences of losing the ability to fund accessible transport, pay for prescriptions or attend medical appointments, support a family member or pay utility bills could lead to a higher demand on support from the NHS and/or councils (i.e. increased hospital and/or residential care support) and a cost to the public purse which may indeed supersede that of the total current costs of Disability Living Allowance (DLA).

2.4 We believe extending the qualifying period from 3 to 6 months will push many disabled people into debt and place extra burden on both individuals and families.

2.5 We believe the longer qualifying period may prevent some people staying in work who experience a sudden injury or illness with longer-term implications.

2.6 We understand that the DWP have clarified that all DLA recipients are ‘disabled people’ in Welfare Reform Bill documents. We believe the DWP has a duty to promote disabled people’s equality of opportunity which we believe is being ignored in plans to considerably reduce support.
Whether automatic entitlement should apply to people with some conditions or impairments and whether some people should receive awards for indefinite periods

3.1 We would concur with the proposal that people with a terminal illness will automatically receive the daily living component enhanced rate and will not have to satisfy the period condition for the mobility component.

Implications of a six month qualifying condition

4.1 We believe extending the qualifying period from 3 to 6 months will push many disabled people into debt and place extra burden on both individuals and families.

4.2 We believe the longer qualifying period may prevent some people staying in work who experience a sudden injury or illness with longer-term implications.

Extent PIP will act as a gateway to other benefits, including carers allowance and motability scheme

5.1 We believe that access to passport benefits that are within the jurisdiction of the Government (e.g. Carer’s Allowance) should be given careful consideration.

5.2 We believe that, as a minimum, the criteria for accessing Carer’s Allowance (for example) should be on a par with current DLA criteria/entitlement.

5.3 How the above would work in practice, however, cannot be clearly ascertained at the moment since the Government have not yet produced details on the point system.

5.4 Given the above, we believe that further scrutiny of this question should take place after full details of the PIP points system have been determined.

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; the extent to which aids and appliances should be taken into account in the assessment

Points to be awarded

6.1 The draft assessment provides no indication of the points award for each of the criteria. Without these it is impossible to ascertain the thresholds being proposed for PIP at the standard and enhanced rate. The lack of information
on scoring makes it particularly difficult to comment on the draft criteria and effectively engage with the Inquiry on this matter.

6.2 We note the proposal to publish the points along with the next draft regulations on October and would encourage further consultation at that point.

_List of essential activities_

_Essential activities limited_

7.1 We believe the list of essential activities is very limited indeed and needs to widen to at least include activities surrounding managing money effectively, staying safe, assistance at night and moving around inside the home.

7.2 The proposed descriptors seem to address a much narrower range of issues than DLA currently does.

_Medical model_

7.3 Similarly, the criteria seem to be designed around the medical model of disability, rather than the social model. What is meant by that is that they look predominantly at the medical impact of an individual’s impairment rather than how this interacts with society to create barriers to independence.

_Repeatedly, reliably and safely_

7.4 There is nothing in the criteria (or in the regulations) that would act as a prompt to ensure that individuals must be able to undertake an activity repeatedly, reliably and safely, despite this being mentioned in the accompanying information. We therefore recommend that the wording of ‘repeatedly, reliably and safely and without significant pain, fatigue or distress’ should be included expressly within each descriptor.

7.5 Similarly, we believe that, in order to fairly and accurately assess the impact of a fluctuating condition, the applicant needs to be asked about the frequency, severity and duration of their condition. It may be that such a measure is tagged onto the assessment as a separate descriptor or it could be integrated into the descriptors themselves.

_‘Continual assistance’ and intermittent assistance’_

7.6 We believe the use of ‘continual assistance’ or ‘continual prompting’ versus ‘intermittent assistance or prompting’ will be difficult to interpret and apply, and fails to understand the reality of the support that people need.

7.7 We would recommend that in the context of assistance the term ‘substantial’ is used (rather than ‘continual’) and in the context of prompting the term ‘repeated’ is used.
7.8 If the definition of ‘prompting’ is retained we believe it should be widened to include other forms of communication such as telephone or e-mail rather than simply the physical presence of a person.

7.9 Also, in the planning and buying food and drink section there should be a lower threshold than ‘continual’ for prompting since certain claimants may need ‘intermittent’ prompting to complete the activity in full. Certain claimants may find that they can do part of the activity then need some prompting before going on and completing the next part of the activity (e.g. people with short term memory problems/people with mental health problems who lack motivation).

Aids and adaptations

7.10 We welcome a commitment to recognise that those who rely on aids and adaptations nevertheless face barriers, by awarding some points to individuals who can complete activities only with the assistance of an aid or appliance in some activities.

Supervision

7.11 We are concerned that the draft activity tests do not take into account the full range of needs that currently fall within the ‘continual supervision’ criteria of the care component of DLA. We note the only explicit reference to supervision in the technical note is for avoiding overdoses of medication. Many needs encapsulated under supervision for DLA do not appear to fit comfortably with the proposed activity tests.

7.12 We have the following concerns on what we believe are important omissions.

7.13 There is no recognition in the draft activity test of the risks faced by people who are prone to falls generally and we would endorse an approach that specifically relates to falls. There does not seem to be any recognition at all that many disabled people have difficulty moving around indoors and may require someone to be with them because of the risk of falling.

7.14 Also, people with certain mental health conditions or cognitive impairments may place themselves, or others, in danger either through deliberate action or an inability to take normal precautions. The only recognition of this is in using a conventional cooker. There is no recognition of any risks from the use of heaters or other household appliances.

7.15 There is no reference to help needed for people who are at risk of deliberate self-harm.

7.16 We would recommend the continual supervision route to benefit is retained in the PIP assessment or an additional activity of ‘staying safe’ is added and appropriate descriptors devised.
Managing medication/Managing prescribed therapies other than medication

7.17 On the point regarding taking prescribed medication at the appropriate time, we believe it is far too prescriptive to limit the definition to prescription medicine and should extend to all medicines that are ‘reasonably required’.

7.18 We are concerned that ‘monitoring health conditions’ and ‘managing prescribed therapies’ may be interpreted narrowly, and will not extend to cover the broad range of activities that may be involved with managing a health condition and maintaining general health. For example, exercise, accessing social support networks, maintaining a routine or certain activities, or complementary therapies may not be ‘prescribed’ by healthcare professionals, but may be an extremely important element of someone’s management of their physical or mental health condition. All of these could entail significant additional costs and support.

7.19 By focusing simply on prescribed treatments, those with conditions for which there are few licensed treatments available (such as progressive forms of MS) are less likely to be able to access support through PIP, although the lack of support and treatment they may therefore receive from the health system may mean that their needs are greater.

7.20 We would favour descriptors which have a broader outlook and which would include not only managing medication and prescribed therapies, but also maintaining a healthy lifestyle.

Assistance at night

7.21 Some disabled people’s needs are at night only (e.g. can deal with spoiled clothing during day but not at night if incontinent). As such, we would recommend an additional activity relating to the need for assistance, prompting or supervision during the night be introduced and appropriate descriptors devised.

Washing, bathing and grooming

7.22 We believe that ‘below a level of self-neglect’ sets a very low standard permissible by Government and could prevent disabled people actively participating in general life. We also believe that such a definition could be construed as a breach of the Equality Act need for DWP to promote equality of opportunity of disabled people.

7.23 We believe that this wording should be replaced by ‘to an appropriate level’ and this should be interpreted subjectively, based on the individual’s lifestyle.

7.24 The focus on cleaning the body, brushing teeth and cleaning and brushing hair means that the descriptor does not take into account the ability
to maintain hygiene beyond the body. This would include washing clothes and keeping a clean and safe living environment.

7.25 We recommend that a separate descriptor should be added to consider the ability to maintain a clean and safe living environment unaided.

Communicating with others

7.26 We believe the ‘communication’ activity should be expanded to ensure it covers disabled peoples communication needs in all social activities. We believe the principles in the Fairey decision should be upheld.

7.27 We welcome the acknowledgement that communication and social interaction can cause distress, but recommend that descriptor D for this activity does not simply deal with ‘overwhelming’ psychological distress but that there is an additional descriptor that covers ‘moderate’, or at least ‘significant’ distress.

7.28 We believe the communication support activity definition (i.e. support from a person trained to communicate with people with limited communication abilities) is too restrictive and should be extended to include other persons who provide communication support (e.g. family members) where it is reasonably required.

Cooking

7.29 The focus on use of microwaves and eating microwaveable frozen food appears to contradict the Government’s own initiatives for healthy eating/reduce high salt intake which emphasises the use of fresh food rather than frozen/ready prepared. Also, certain claimants may have special diets that mean avoiding microwavable/frozen foods and this is not factored into the definition of ‘simple meal’ provided.

7.30 Similarly disabled people’s needs may be undermined by a test which may prevent someone accessing support who can only manage simple buttons on a microwave and purchase, cut and cook fresh products.

7.31 Also, it is particularly important that people’s ability to prepare a meal repeatedly, reliably and safely is taken into account and believe that this wording should be used on the face of the descriptor.

7.32 We believe ‘assistance’ should be interpreted broadly to cover supervision, as well as direct physical assistance.

7.33 The concept of ‘aids or appliances’ should also be widened to cover, for example, the need to buy pre-chopped vegetables or other pre-prepared food, or the increased use of materials, ingredients or utilities.

7.34 In addition, preparing a meal should extend to being able to identify and select ingredients, and read and understand cooking instructions, issues
which may be problematic and require assistance for people with visual or cognitive impairments.

**Managing toilet needs or incontinence**

7.35 We are concerned that this descriptor does not take into account any difficulties experienced in getting to a toilet while inside or outside the home, or the frequency of toilet needs. Getting to the toilet is often more difficult at night time, and some people may need assistance with this. The need for assistance throughout the night should be particularly addressed.

7.36 Another difficulty for people with continence problems or leakage from stoma appliances is the need for assistance with changing bedding during the night.

**Planning and following a journey**

7.37 The guidance note mentions safety, but as with other descriptors, we believe that this needs to be in the text of the descriptor itself. Guidance and supervision to avoid danger must be included. For example, for people with a visual impairment, support may be needed to manage if something unexpected and unpredictable happens to disrupt their route.

**Moving around**

7.38 We believe the test should include some consideration of the ability to get up and down stairs. The lack of ability to do this can make a wide range of places inaccessible, and indeed can determine the ability for some people to get around their own home. The ability to stand and sit should also be considered. Those who experience significant fatigue when standing for a period of time will find it particularly difficult to make use of public transport, as will those who struggle to rise from sitting to standing and they may therefore rely on expensive taxis, or require support or a companion when travelling around.

7.39 The proposed assessment fails to consider moving around/navigating indoor environments beyond the home. For example, people who are blind or partially sighted may need support to be made aware of obstacles, locate toilet facilities, entrances and exits or help if one stumbles or falls in an unfamiliar area.

7.40 The assessment considers a very narrow range of activities and does not consider a person’s ability to engage in social activities, maintain relationships, engage in community activities, volunteering or employment, or to access local services. The current DLA claim form asks about things you would like to do and the support you would need for that. We recommend that this consideration is retained in the new assessment to ensure that PIP promotes participation and independence in its fullest sense, rather than the bare minimum.
7.41 We note there is no inclusion of pain/distress on walking around compared with the DLA high rate mobility component. The lack of such a qualification implies that if someone can walk 50 metres regardless of the level of pain or distress they may experience as a result, they won’t get any points. We believe this is a significant departure from the test in DLA. We believe DWP considers the ‘safety’ issue to be resolved elsewhere but would welcome an explicit reference to ‘and without experiencing discomfort’ at the end of the relevant a-g (ii) descriptors.

**Delivery of 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; and interaction with other eligibility assessments**

**Medical assessments**

8.1 We take the view that any assessment as to whether someone is entitled to PIP should be carried out by a Department for Work and Pensions (DWP) decision maker and not driven (or, indeed, instead of) a medical assessment carried out by personnel such as an ATOS Health Care Practitioner.

8.2 We believe that the Inquiry should take full cognisance of the conclusions drawn by the Harrington Review regarding the problems with, in particular, the quality of medical assessments made by ATOS personnel and the need for the DWP’s decision maker’s to take responsibility for making decisions on entitlement. One year on from the start of the review we, as an organisation, have found no improvement with respect to either of the above and would like to state some concern over the ability of ATOS to deliver fair and accurate medical assessments.

8.3 Given the above, we would not endorse a medical assessment gateway approach at all. Also, we believe that, claimants with severe conditions (most specifically people with severe mental health problems) will find it much more difficult to engage with the medical assessment process in a gateway approach leading decreasing opportunity of access for those with the most severe conditions/limitations which would surely undermine the purported main principles of PIP.

8.4 We do not believe it would be beneficial for claimants to have to undergo medical assessments for different benefits with different criteria (e.g. ESA and PIP) at the same time. Medical assessments can be very demanding experiences for disabled people and we believe that requiring claimants to participate in two medical assessments on the same occasion could prove onerous for the claimant and lead, potentially, to an undermining of the accuracy of the assessment.

8.5 Regarding any potential tendering exercise, we would ask the Government to take cognisance of the poor performance of ATOS thus far.
The steps the DWP needs to take to ensure that it’s reform proposals are clearly and effectively communicated to claimant and the general public

9.1 We believe the DWP should carry out the following as a minimum –

- an extensive media campaign to educate both the disabled community and their carers nationally;
- make available details to disabled people representative groups (including welfare rights organisations who provide local services) who will be able to ‘educate’ their networks;
- contact individuals already in receipt of DLA directly to advise on any impending changes on how they may be affected;
- ensure the availability of accessible leaflets/briefing notes on the subject are made readily available.

Transitional arrangements

10.1 We believe that all current DLA claimants should not be migrated over to PIP pending the end of any current award and income levels be protected.
Written evidence submitted by the Scottish Campaign on Welfare Reform (PIP 48)

Introduction
1. The Scottish Campaign on Welfare Reform (SCoWR) is a coalition of leading civil society organisations. Members work with people experiencing exclusion and poverty across Scotland. This response outlines the consensus of opinion which exists among SCoWR members over key concerns with the UK Government’s proposal to replace disability living allowance (DLA) with personal independence payment (PIP). Many of our members are also providing their own, detailed responses. This response is intended to complement those provided by individual members.

Our response
2. The SCoWR manifesto sets out the five reforms that our members believe are necessary for an adequate welfare state:

- Increase benefit rates to a level where no one is left in poverty and all have sufficient income to lead a dignified life
- Make respect for human rights and dignity the cornerstone of a new approach to welfare
- Radically simplify the welfare system
- Invest in the support needed to enable everyone to participate fully in society
- Make welfare benefits in Scotland, suitable for Scotland

Increase benefit rates to a level where no one is left in poverty and all have sufficient income to lead a dignified life
3. The Government hopes to save £1.45bn of annual DLA/PIP expenditure by 2014/15. To put this figure in context; annual expenditure on all those currently in receipt of lowest rate care is approximately £900m. It is clear that this saving won’t be achieved without a significant reduction in the number of claimants. We oppose this objective, because whatever the fiscal situation, the number of disabled people in society already exceeds the number of DLA claimants. It is not justifiable to penalise some of the most vulnerable people by removing this vital support – particularly when plans to bring in the new benefit and re-assess all current claimants are estimated to cost £675m.

4. We question the Government’s claim that the objective of the reforms is to facilitate independent living. In reality, many disabled people will find their ability to live independently seriously limited by these reforms. We would also challenge the implication that these reforms are necessary to combat a rise in fraudulent claims. The DWP’s own statistics estimate DLA fraud at 0.5 per cent, and that the rate of overpayments caused by departmental error is significantly higher. The increase in the number of DLA claimants can largely be explained by the overall increase in population since 1992 and the fact that the UK has an ageing population. Furthermore, an individual must be under 65 to claim DLA for the first time, but once s/he has started receiving it s/he can continue to do so regardless of age. In 1992, all claimants were under 65 – but there are now claimants up to the age of 84.

5. The Government has not specified the rates at which the new benefit will be paid. We believe that the Government should increase the rates at which the components are paid to reflect the reality of the extra costs that disabled people face. The Government’s own figures show that the rates of benefit are not adequate to meet the costs that many disabled people face.

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1 A full copy of the SCoWR manifesto can be downloaded from the Poverty Alliance website here: http://www.povertyalliance.org/campaigns_detail.asp?camp_id=8
2 DWP, November 2010, Disability Living Allowance caseload for lower rate care
3 DWP (February 2011) Disability Living Allowance Reform Impact Assessment, 2
4 DWP, July 2011, Fraud and error in the benefits system: Preliminary 2010/11 estimates, Table 2.1 http://research.dwp.gov.uk/asd/asd2/fem/fem_oct09_sep10.pdf
face. Research estimates that the additional costs attached to having a disability vary between £7.24 to £1,513 per month\(^5\).

6. We are also concerned that the descriptors proposed to assess eligibility for PIP are not accurate proxies for the added costs of disability. For instance, in relation to activity two of the assessment ‘Preparing food and drink’, the distinction between different descriptors (and therefore different points allocations) do not relate to a change in daily living related costs. Someone who needs ‘continual prompting’ to prepare a simple meal will have the same care costs as someone who needs ‘continual assistance’ to prepare that meal. Other descriptors require further clarification. For instance, a person will be less likely to qualify for the mobility component of PIP under Activity 10 if they ‘can follow a simple journey’. A simple journey is defined a ‘travel to a familiar destination that requires walking and/or a single mode of transport such as a bus’. We are concerned that this might be interpreted to include the ability to arrange a door to door taxi journey – which will clearly be very costly. There is a need for the government to provide further information and to reassess the extent to which these criteria act as a proxy for a need for financial support.

7. These reforms will undermine the dignity and violate the human rights of thousands of disabled people. The proposed assessments are similar to the work capability assessments for ESA, which has been widely criticised, including by the independent Harrington review. The review is a damning indictment of the way in which the assessment system functions. Despite this the Government is pressing ahead with similar proposals for PIP.

8. Where sufficient supporting evidence is available, claimants should not be forced to go through a medical assessment. Furthermore, it is vital that the PIP assessment is planned, designed and administered with the dignity and respect of disabled people as the starting point. Assessments should be carried out by independent specialists relevant to a person’s condition, and whose focus is on the information provided by claimants and people who know them well. Training should be provided to those carrying out the assessment to ensure they have an adequate knowledge of the social model of disability, human rights and independent living. There is also a great need for independent advocacy to ensure that those being assessed understand the process and can engage with and challenge it. This should be government funded and widely available.

9. The Government’s argument for reviewing all PIP awards is the apparently large number of indefinite DLA awards that have never been checked. This has created the impression that a high proportion of indefinite DLA awards are inaccurate, without providing any evidence that this is the case. Reassessments will cost money, and will involve needless distress to disabled people with lifelong conditions. In a time of austerity any proposal to spend public money on an increased number of assessments should be subject to the greatest scrutiny.

9. Furthermore, assessors should not be set targets in relation to outcomes, processing time or scores. Any payment to a contractor defined by numbers of assessments performed automatically drives down the quality and means costs are shifted to tribunals and advice organisations. Instead, as described above, assessors should be required to carry out their functions within an ethical framework which makes treating disabled people with dignity and respect their performance bench mark. They should also be encouraged to perform well by way of fines when they make too many wrong decisions (ie. decisions that are later overturned at appeal).

10. According to the Government, the purpose of PIP is to “contribute to the extra costs of overcoming the barriers faced by disabled people to live full and active lives.” However, the descriptors do not assess the individuals’ capabilities in relation to certain everyday activities – often in violation of their human rights. Examples include the fact that there is nothing in the assessment to measure a person’s ability to access information, despite this being a right under Article 21 of the United Nations Convention on the Rights of People with Disabilities (UNCRPD). Nor is there any measure of the individual’s ability to participate in cultural life, leisure recreation and sport. This is particularly surprising given that, according to the Government, ‘participation’ is the objective of these reforms. The right to the highest attainable standard of health could also be undermined because - although there is reference to the ability to prepare a meal - there is no mention of that meal being balanced or nutritious. Eating toast and cereal for every meal is not acceptable. Furthermore, there is nothing in the assessment about a person’s ability to handle their finances or budget. Finally, there is no equivalent to the ‘day supervision’ test employed under DLA. This will impact people whose main impairment arises from unpredictable, episodic conditions such as epilepsy.

11. We are strongly against the Government having the power to remove mobility related PIP from people living in care homes. There is no rational justification for this measure, which has the potential to undermine independent living and violate the human rights of around 80,000 people across the UK. This view is shared by the Social Security Advisory Committee, which has recommended that these measures undermine the objective of supporting disabled people to live independent and active lives. For more information see Capability Scotland’s research on the issue.

12. There is also a more general concern that the dignity of disabled people is being undermined by the continual introduction of laws and policies aimed at reducing costs. There are too often portrayed as minimising fraudulent claims and making sure disabled people don’t take more than they deserve. This is contributing to the construction of disabled people as liars and cheats.

Radically simplify the welfare system

13. We appreciate that the DLA application form is too long and complicated, and that many claimants need significant assistance and time to complete it. The proposed PIP assessment, however, risks adding further complexity to the decision-making process. The single reform which would most simplify the process and vastly reduce administrative costs would be to extend the number of conditions that give rise to automatic entitlement. This would allow claims to be decided efficiently and awards to be more consistent. There should still be the option of a claim based on personal circumstances where costs may be greater than normal for claimants with a particular condition.

14. Furthermore, the removal of one rate of one component is not a ‘simplification’ so much as a measure to save money by removing entitlement from large numbers of existing claimants. Reviewing that claims process to make it more claimant-friendly and increasing automatic entitlements are better ways of achieving this end.

Invest in the support needed to enable everyone to participate fully in society

15. DLA is a vital lifeline to many and to withdraw it from claimants is to exclude them further from society. The proposals suggest that only those in the greatest need will be eligible. This is entirely unacceptable. Eligibility should not be based on a person’s ability to complete

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6 http://ssac.independent.gov.uk/pdf/DLA-Consultation.pdf
7 http://www.capability-scotland.org.uk/media/71348/how_am_i_going_to_put_flowers_on_my_dad_s_grave_-_how_care_home_residents_use_the_care_component_of_their_dla_april_2011.pdf
‘everyday essential tasks’; but on whether and to what extent that person requires extra income to live independently. Understanding need only in terms of ‘essential activity’ is to completely disregard the principles of independent living, participation and basic human rights. The suggestion that it is somehow progressive to redistribute in favour of those most in need of support to function is flawed.

16. Furthermore, the same group who will lose eligibility for PIP because their need is not judged to be great enough will be the same people who are disadvantaged as a result of changes to ESA and cuts to local authority care packages. This is not only wrong, it will result in the deterioration health and in people’s ability to live independently. As the Dilnot Commission on adult social care recently acknowledged, meeting lower level needs is essential to ensure prevention of higher or crisis level needs.8

17. Other areas of the assessment which will undermine participation include:

- The medical nature of the assessment
Eligibility under the plans will be based on a medical assessment and on evidence submitted by medical professionals such as GPs and occupational therapists. If the assessment is to be relevant and meaningful the individuals themselves must also to be given the opportunity to submit evidence, particularly in relation to environmental and societal factors which prevent them from living independently and participating in society.

-Poorly considered assessment criteria
There is a failure to appreciate the interaction of the assessment criteria and descriptors. For instance, a person’s ability to take medication is giving a low weighting in relation to other aspects of the assessment. This approach disregards the fact that if a person cannot reliably take medication, they may not be able to participate in the other activities. The Government also proposes that a person’s ability to use aids and adaptations to get around should be considered in assessing their mobility. However, the social and physical barriers to mobility are not removed by the possession of a wheelchair or a stair lift. While some wheelchair users may have an electronic chair and a ramp to their front door, they may also live at the top of a steep hill which they cannot negotiate or in an area with no accessible buses. This provision is also likely to result in higher rate mobility component being withdrawn from wheelchair users. This will be particularly problematic in remote rural areas and as such it will have a disproportionate effect on disabled people in Scotland.

-Lack of clarity
The Government has stated that in order to be assessed as capable of doing something, they must be able to do it “repeatedly, safely and in a timely manner”. This is not contained in the draft regulations themselves. Furthermore, the government has not explained how these terms should be interpreted. How often should a person be able to repeat things to be classed as able to do them ‘repeatedly’?

There is currently very little detail in relation to if/how PIP will apply to children and individuals over pensionable age. We urge the Government to delay any changes to the entitlement of these groups until the effect of the reforms has been thoroughly assessed and any problems resolved. For children these reforms represent an opportunity to improve on the DLA assessment and, in particular, the ‘significantly greater needs’ test, which is hard to satisfy even with significant extra costs. The evidence on early intervention suggests that more generous entitlement criteria will reduce overall costs in the long run and repay the investment in them.

8 Dilnot Commission (July 2011) Fairer Care Funding, 21
-Assessment of fluctuating conditions
We welcome the consultation’s acknowledgement of the need to take account of needs which vary over time, however, there is no explicit acknowledgement of the existence of varying conditions in the regulations. If people with fluctuating conditions are to be fairly assessed then less weight must be given to their medical assessments and more on any supporting documents submitted by practitioners who know the claimant. Again, we believe, the most effective way of providing consistent decision making and clarity to claimants would be to use an automatic entitlement for people with particular fluctuating conditions.

People with mental health conditions often have fluctuating conditions, meaning that they may be assessed on a ‘good day’ but this would not be an accurate assessment of them when their condition is affecting them. There is great need for independent advocacy in this area. Also, there is no appreciation of how fluctuation in environment will affect conditions.

-New conditions
The extension of the qualification period will act to exclude disabled people at the very time when adequate financial support can make the most positive difference. While other areas of policy are rightly focussing on the importance of early intervention, this proposal is regressive in the extreme. Using Government figures as a basis, the additional cost of six months of disability could range from £43.44 to £9,078. Lack of any support with these costs is unjustifiable and limits the ability of thousands of people to live independently at what may be one of the most stressful times of their lives.

Make welfare benefits in Scotland, suitable for Scotland
20. Whilst neither PIP nor UC will be matters devolved to the Scottish parliament, this legislation will impact on claimants in Scotland in different ways due to its interaction with devolved matters, principally health and social care. Any legislation should explicitly acknowledge the importance of devolved legislation in the areas of health and social care, and build into the regulations the flexibility to account for regional variations.

21. In many cases the removal of financial support will lead to increased reliance on social care and other local authority services. This extra burden on local authorities will be felt disproportionately in Scotland where many local authorities take disability benefits – such as the care component of DLA - into account when they are calculating care charges. As DLA is reduced, so will the available income of service users and, in turn, the amount that local authorities are able to charge for care packages. This will not be the case to the same extent in England, where the Department of Health has issued guidance on fair charging of disabled people.10.

22. Furthermore, the mobility component of DLA is often used to informally subsidise, upgrade or repair publically provided wheelchairs, aids and adaptations. If DLA (or its equivalent) is removed from 20% of claimants, then this burden will fall on local authorities and the NHS.

23. The Government has justified its intention of removing the mobility component of PIP from those in residential care on the basis that all care support and mobility requirements should be met from social care funding. This is not only an unrealistic prospect, but also undesirable and impractical. Research has found that, contrary to UK Government claims, local authorities do not tend to fund mobility costs for disabled people in care homes as part of contractual fees – meaning there is no duplication of funding. Half of disabled people who live in residential care give either the majority or their entire DLA mobility component to their care home. Of these, 40% said that it pays for a Motability car, and 21% said the money

goes towards petrol for staff to take them out. This suggests that much of the burden will fall on local authorities\(^\text{11}\).


1. Introduction

Motability has noted the Committee’s intention to examine the Government’s proposals for replacing Disability Living Allowance (DLA) with Personal Independence Payment (PIP), and in particular, the Committee’s interest in the extent to which PIP will act as a gateway to other benefits including the Motability Scheme.

This note is intended to provide the Committee with an outline of the relationship between the Motability Scheme and disability benefits, and of our understanding of the Government’s plans for PIP and their likely impact on the Motability Scheme.

2. About Motability

Motability is a registered charity (No. 299745), incorporated by Royal Charter in 1988. It was set up in 1977 at the initiative of the Government with the objective of enhancing the mobility of disabled people. In particular, Motability helps disabled people with their mobility needs by enabling them to use their Government-funded mobility allowances to obtain a car, powered wheelchair or scooter through the Motability Scheme.

Customers of the Motability Scheme use their Higher Rate Mobility Component of Disability Living Allowance (HRMCDLA) or War Pensioners’ Mobility Supplement (WPMS) to meet the cost of having a car, powered wheelchair or scooter. The most popular option, chosen by over 95% of customers, is the contract hire of a car. Customers can choose a new car every three years with insurance, road tax, servicing, tyres and breakdown cover all included. A wide range of adaptations and wheelchair accessible vehicles are also available. Scooters or powered wheelchairs are also available instead of a car.

Independent research has demonstrated that the Scheme has a significant social and economic effect in the UK. It provides large numbers of disabled people with independent mobility, enabling them to access employment, education and services as well as facilitating their social activity. The Scheme consistently achieves very high levels of customer satisfaction.

As at 31 August 2011 there were close to 600,000 customers on the Scheme representing approximately 30% of those in receipt of the Higher Rate Mobility Component of Disability Living Allowance and, therefore, eligible to join the Scheme. There are also around 5,000 recipients of the War Pensioners’ Mobility Supplement on the Scheme.
3. Motability and Disability Benefit

Key to the successful and cost effective administration of the Motability Scheme is the existence of a specific mobility related benefit which can easily determine eligibility for the Scheme, and which can be assigned by recipients to be paid direct from Government to Motability. This simplifies administration and removes any credit risk, which would otherwise arise if Motability had to put in place arrangements to collect funds direct from its customers, thereby contributing significantly to the cost effectiveness of the Scheme. In our response to the Government’s consultations on PIP, and in our discussions with the DWP, Motability has stressed the importance of maintaining these features in the design of the new PIP.

4. Personal Independence Payments

At an early stage in developing its plans for PIP, the Government made it clear that it was committed to ensuring that the operation of the Motability Scheme would continue to be facilitated under the new benefit arrangements. Motability has had a series of constructive exchanges with Ministers and officials at the DWP, and, although several issues of detail remain to be settled, we are satisfied that, as currently planned, PIP can be expected to provide an effective gateway to the Motability Scheme. In particular the decision to incorporate a mobility component within PIP, as within DLA, (albeit with different criteria) provides the basis for a clear linkage to the Motability Scheme.

There are still some uncertainties about the impact of the Government’s proposals on the Motability Scheme. Precise details of the linkage between PIP and the Scheme, and the rate of payment of the relevant PIP component, remain to be settled; the number of eligible recipients of PIP will clearly have a bearing on the size of the Motability Scheme going forward; and the transitional arrangements will need to be carefully handled particularly if, as a result of the changes, significant numbers of current Motability customers lose their eligibility for the Scheme. Nevertheless, Motability expects to continue to work with the DWP to ensure that these issues are resolved in a way which continues to facilitate the operation of the Motability Scheme.

5. Conclusion

Motability is pleased that the Government remains committed to supporting the Motability Scheme through its reform of DLA. We will continue to work with the DWP to ensure that PIP becomes an effective gateway to the Motability Scheme so that disabled people continue to enjoy the freedom, independence, and access to employment, education and social activity which the Scheme provides.
Written evidence submitted by David Gillon (PIP 50)

This submission is in my personal capacity as a disabled person.

Summary
1) This submission addresses my views on the introduction of PIP both in light of the potential effects on disabled people in general and based on my analysis of how DLA has failed to address my own needs as a person with a substantial mobility impairment.

The need for DLA reform:
2) As an individual I have never experienced any difficulty in understanding the structure of DLA, the suggestion that people cannot understand it seems perplexing. I suspect the problem has been access to information about the scheme, rather than then structure of the scheme.

3) Turning to the supposedly inexplicable rise in caseload, this has now been thoroughly explained by independent figures who noted DWP’s failure to account for demographic changes, the continuation of DLA past pensionable age and several other fundamentally vital elements in the analysis. That DWP failed to consider these in its analysis casts the entire analysis in doubt.

4) While not currently in receipt of DLA myself, I note the absolute terror that reviews bring to friends and acquaintances, note that stress worsens the symptoms of very many disabilities, and believe that any systematized review process must endeavour to limit reviews to the absolute minimum required and that in many cases the illness or disability in question may make it appropriate to choose an infrequent review period, or even retain the ‘lifetime award’ period of DLA. No matter the attractiveness of reviews to the general public, the DWP and ministers should not be allowed the luxury of ignoring their very real health consequences.

5) The suggestion that PIP should be accompanied by a 20% drop in budget is clearly government by political fiat, without any consideration of, or concern for, the effect on disabled people. If there are problems with the administration of DLA they do not require a cut in budget. If there are problems with the complexity of DLA they absolutely do not require a cut in budget, as simplification should expand the client population through simple accessibility. A 20% cut in PIP rates in comparison to DLA would be disastrous to the entire set of clients, a 20% cut in eligibility will be catastrophic for those affected. Cutting a disabled person from eligibility for PIP does not make their disability miraculously disappear, their care needs will remain identical, their mobility will not be approved. However the 20% cut is framed, the reality is that it is taking away needed support from disabled people for the convenience of a political agenda.

The implications of a six month qualifying period.
6) Six months as an absolute cannot be defended logically, the disability and needs of someone suffering, say, a complete spinal injury, are immediately apparent, while many conditions take far longer to produce a firm diagnosis, personally I am still waiting for a clear diagnosis after 23 years. Care and mobility needs may set in
immediately and six months is a long time for people to wait for support, particularly if they do not have extensive savings and may be facing severe reductions in incomes. It would be more appropriate to allow immediate applications based on demonstrated need, but to make them conditional for the first six months, with a reassessment at that point to determine the long-term need.

7) This will also cause severe problems for people facing variable conditions. As a rule of thumb I am able to say that my fluctuating disability operates at a base disabling, level for around 9 months of the year, and at a more severely disabling level for 3 months. Those figures could as easily be around six months each and the six month qualifying period would seem to mean that someone who needs support at the highest levels for almost, but not quite, six months of the year would never be able to access it.

The extent to which PIP will act as a gateway to other benefits

8) This is an area of concern to me as someone currently receiving a Blue Badge through the discretionary criteria. PIP mobility criteria are suggested as the governing criteria in discretionary awards through local councils, so any change in PIP assessments has a potential flow-through into the discretionary criteria, without necessarily being clearly defined. There are mobility needs that are simply not covered by the PIP criteria, for instance I simply cannot access normal width car-parking spaces; there is insufficient space available for me to get out of the car, with crutches and unstable joints, without injuring myself. I absolutely have to park in a disabled bay or on the street, and a Blue Badge is required for either. This factor, and other individual needs, are simply not considered for PIP eligibility, but the discretionary criteria retain, in some councils at least, the flexibility to recognise them as needs warranting issuing a Blue Badge and it is vital that this flexibility is retained.

9) Equally Motability is a vital lifeline to many mobility disabled people, and currently gateway-ed through DLA, yet DLA restricts itself to a level of mobility impairment far more severe than that at which mobility impairment begins to seriously restrict the lives of disabled people. Is it appropriate to restrict Motability eligibility to PIP’s higher rate of mobility allowance, or is there a sound case to be made for shifting it down to a lower level of access? As a self-funding system, increasing Motability eligibility would not come at any additional cost to government and would potentially benefit the lives of very many disabled people who find themselves struggling to access the environment.

The design of the PIP assessment

10) I do not currently claim DLA, my assessment is that I am currently borderline for Higher Rate Mobility, but the structure of the assessment criteria make a claim difficult. I can usually walk further than 50 metres, some days far further, but I am likely to have severe pain, to the ‘virtually unable to walk’ level, set in within 50 to 100 metres, and as the day progresses the distance before the pain manifests becomes shorter and shorter, until by the end of the day I am struggling to walk at all. Yet there seems to be little clear guidance around repeatability in the existing system, and none whatsoever in the draft PIP assessment criteria.
11) Equally problematic is whether 50m is an appropriate measure of severe mobility impairment; in my local environment none of the buildings I need to access - bank, chemist, post office, Job Centre, etc. - lie within 50m of easily available disabled or on-road parking and very few are within 100m, some are over 350m from available parking. The draft PIP assessment criteria introduce 200m as a measure of mobility difficulty and this is a very welcome change, particularly if it is accompanied by making the lower mobility rate of PIP relate to this (a possibility the draft assessment criteria seems to be remarkably silent on). If this is the case, and if not I would strongly suggest it be made so, then this will make the Mobility component of PIP useful to many severely mobility impaired people who currently fall just short of the 50m/virtually unable to walk standard. In company with this I would urge that the criteria for Blue Badge eligibility and access to Motability be shifted to the lower rate. The need for both of these reasonable adjustments to disability kicks in well in advance of being unable to walk 50m and this is a minimal cost opportunity for the government to address that and show that PIP is not simply about cutting the budget by 20%. In fact potentially regularising my access to the Blue Badge is far more important to me than the payment element of PIP.

**Fluctuating Conditions**

12) My understanding of the currently proposed assessment criteria is that fluctuating conditions will be covered where they affect the disabled person for most of the time. However, the logic behind this means that someone with a disability which leaves them utterly immobile and in need of 24 hour care, but only for 182 days a year or less, would receive no support whatsoever. My own experience of fluctuating conditions is that I have both short-term and long-term variability in symptoms, and this is far from an uncommon pattern. I can shift from low pain levels to utterly disabling ones literally between one step and the next, and equally I can have periods of months of elevated pain levels. Even if I am currently experiencing no symptoms whatsoever, I have to plan my life around the assumption that I am, because the consequences of being caught unprepared simply aren’t tolerable. A fluctuating condition imposes restrictions and support needs on your life even while not currently ‘active’ at its most extreme levels.

**The Applicability of Mobility Aids in the Assessment**

13) We live in an inaccessible environment; the Disability Discrimination Act has not altered that fact in 15 years. At least half the shops on my local high street have stepped entrances, most of the high street is hundreds of metres from the nearest disabled parking and current redevelopment proposals will actually worsen that. The local Job Centre is several hundred metres from the nearest disabled parking, even the ATOS Assessment centre, with a solely disabled clientele, is over 100 metres from disabled parking. Access can also be deceptive, the size of a building or complex and the time available to negotiate it are also profound factors in accessibility. The availability of a mobility aid does not magically remove accessibility issues and I am not certain that this distinction, together with the limited impact of the DDA on accessibility, was understood by those drafting the proposed legislation. While it is reasonable to assess a disabled person’s mobility using mobility aids, this should only take into account the aids they habitually use and take full notice of the fact we live in an overwhelmingly inaccessible environment.
14) Thankfully the rumoured proposal to use an ‘imaginary’ wheelchair in the assessment seems to have disappeared from the draft, but with another draft to come I feel I have to address the potential of its restoration. I currently walk with crutches, I am told by my medical advisors that I would be at the lowest priority for a wheelchair from the local NHS Wheelchair Services, offered only the most basic model, yet I have very complex seating issues as a result of my spinal condition. A wheelchair suitable to my actual needs would certainly need to be individually fitted, potentially to offer tilt-in-space-seating, and instead of the £50 of a basic NHS model we are suddenly talking about a cost in the several thousands of pounds for a suitable manual wheelchair, a similar powerchair would be a five figure sum. For very many disabled people these are inaccessible sums. Obviously the availability of an appropriate wheelchair cannot be simply assumed as the virtual wheelchair proposal suggested.

The approach to tendering for the assessment contract; who should make the award decisions;

15) The Harrington Year 1 report clearly makes the case that there have been major problems in the operation of WCA over and above issues with the procedure itself. I would argue that as a result of these failures there has been a complete breakdown in trust between the DWP’s contractor, ATOS Origin, and disabled people as a whole. That trust is vital if the PIP contract is to be perceived as operating in a fair and equitable fashion and I would therefore propose that whoever is contracted to operate the assessments should do so under the aegis of an independent supervisory board of which 50% plus one of the members are required to be disabled persons. I would additionally suggest that the contract require the contractor to take active measures to improve the confidence of disabled people in its operations, while restricting it from activities that would not be available to a government agency, c.f. the current attempts by ATOS Origin to close down discussion of its operation by its disabled clients through legal action which is further poisoning the lack of trust between the DWP’s contractor and its clients.

16) Turning to the operation of the assessments, I would strongly urge that it be made a requirement in law, not simply in contract, that all assessment centres must meet, from day one, set accessibility standards, with multiple on-site disabled parking spaces, wheelchair access throughout, seating suitable to the needs of a clientele universally experiencing limited mobility and/or serious illness, and so on. My preference would be for the medical assessment of need to be conducted by the claimant’s own nominated physician, but failing that a statement from my own consultant points out a major issue in the fairness of assessments: ‘It is almost impossible to get a doctor who is not a pain management specialist to understand how disabling chronic pain really is’. If assessments are not carried out by the claimant’s own physician, then the system must provide for them to be assessed by someone who is a specialist in the appropriate area. It is not acceptable for a claimant to have to explain to the assessor what their disability is, as has been happening regularly in WCA assessments.

17) Equally the operation of the ATOS Origin WCA contract contains major areas of concern. The unsustainably high rate of appeals raises immediate concerns about the absence of performance criteria and quality control mechanisms in the WCA contract,
while the secrecy surrounding the identity of the contractor responsible for monitoring the performance of the ATOS Origin complaints system creates the inevitable supposition that ATOS are operating a Star Chamber system of justice. The contract for PIP assessments must include 1) strict performance targets, 2) penalty clauses related to these, 3) open external quality auditing with published annual reports, 4) an independent and open complaints assessor operating in ombudsman fashion.

The steps DWP needs to take to ensure that its reform proposals are clearly and effectively communicated to claimants and the general public.

18) I have read the draft assessment criteria, and I struggled to understand how they would function, no matter that I have a degree in computer science and have written complex, safety critical, work instructions. Communications from DWP explaining the reform need to be worded in plain English so that they are accessible to all, including those in the claimant population with intellectual disabilities, and they need the detail and nuance to explain how they will work in actuality that is singularly lacking in the first draft proposals.
Summary

1. The London Borough of Lambeth welcomes the chance to comment on the proposal to replace DLA with the Personal Independence Payment.

2. We are aware that receiving an award of DLA makes a profound difference to the lives of recipients, their choices and potential for social inclusion. DLA promotes independence and is an important component in funding innovative supported living schemes and the personalisation agenda.

3. This issue is important to Lambeth for many reasons. We have over 12,000 DLA claimants of working age in Lambeth. Nearly half have mental health support needs. Compared to other local authorities, Lambeth’s population has significant number of people with severe and enduring mental health problems.

4. The ESA migration has been difficult for many Lambeth residents, but has especially impacted on those with mental health support needs. We are concerned that DLA reform does not take account of lessons from the ESA migration. One of the clear lessons of the Harrington report is the value of an independent review and the value of implementing lessons learnt from the piloting migration project. We would welcome similar for PIP. The piloting of 1000 people by a commissioned provider, assessing the impact of the draft regulations without the involvement of decision makers, does not provide sufficiently robust testing of impact.

5. The Government believes that the introduction of PIP will lead to an increased focus on those with the greatest needs. We have considered the draft regulations and are concerned that the reduction in caseload and expenditure will be achieved by revising the eligibility criteria in a way that will unfairly penalise some groups of disabled people whose additional costs of disability will no longer be recognised within the social security system or where support will be reduced despite them having considerable support needs. We are particularly concerned about the impact on those people with mental health support needs and cognitive impairments.

6. This response focuses on the following issues:
   - 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.
• The implications of a reduction in expenditure, including: the implications of focusing on those with the greatest needs; the number of current DLA recipients who would not be eligible for PIP and the extent to which PIP acts as a gateway to other benefits

• Whether automatic entitlement should apply to people with some conditions or impairments and whether some people should receive awards for indefinite periods.

• The implications of a six month qualifying period

• 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.

• The delivery of the PIP assessment, including who should carry it out

• Lessons to be learned from the Harrington Review of the Work Capability Assessment; and interaction with other eligibility assessments

Need for DLA reform, including: how well understood DLA is; why the DLA caseload and expenditure has increased; the effectiveness of the decision-making

7. The initial DWP consultation document suggests that DLA spending is out of control and is being paid to people for whom it was not intended, yet the DWP’s own research suggests that DLA is significantly under claimed.

8. DLA was introduced at the beginning of a period of expansion in community care with significant improvement in social attitudes around integration and aspirations for people living with disability. This possibly explains why initial expectations of claimant numbers were so out of line with actual outcomes and at odds with the DWP’s own research into under claiming.

9. Fairer charging guidance states that local authorities who charge for delivery of domestic care services should ensure that recipients receive all the financial support from the benefits system to which they are entitled (including DLA). Local authorities worked to improve take up on under claimed benefit through take up campaigns. It has been suggested that, despite this work, take up is as low as 50%.

10. Local Authorities have worked closely with colleagues in health, housing and community organisations to tackle problems around low levels of DLA take up. This has also included working with DWP to secure improvements to the claim form and decision makers’ awareness of where to gather appropriate supporting evidence.
11. We would suggest some of the increased take up of DLA implies that the purpose of the benefit is better understood by a wider range of claimants.

12. The DWP has responded to research around barriers to claiming DLA to ensure the benefit is correctly focused. For example, The Social Security and Mental Health Report (M Hirst & Roy Sainsbury), identified areas of improvement to ensure better reach of DLA, and led to DWP implementing improvements to the claim pack and assessment process to ensure it better met the requirements of people with mental health support needs.

13. The Government believes that the current system has grown too complex and the purpose of DLA is misunderstood and fails to target those in greatest need. However we believe that this can be better resolved through improved communications about the nature and reach of the benefit. In Lambeth, we have recently undertaken take up campaigns which highlighted significant under claiming of DLA, and highlighted the importance of working with key health and social care professionals so they better understand the reach of the benefit, and their clients’ possible entitlement.

The implications of a reduction in expenditure, including: the implications of focusing on those with the greatest needs; the number of current DLA recipients who would not be eligible for PIP

14. A study in 2011 by Anne Corden, Roy Sainsbury, Annie Irvine and Sue Clark called ‘The Impact of Disability Living Allowance and Attendance Allowance’ concluded that for adults, DLA is used to pay for services and items, often to promote independent living and prevent moves into residential or nursing homes.

15. Findings of the report showed that service users often learn about DLA from social workers or health professionals, and through informal sources, such as family or friends. Social workers play an important role in providing information about benefits and offering practical support to complete the application process. Some people might use the money for personal care, others for employment-related training.

16. It has been widely accepted as good practice in tackling poverty for Local Authorities to promote the take up of DLA. This is because the impact of DLA provides a financial safety net and helps service users maintain their independence and because receipt of the benefits made a fundamental difference to their lives and to those of their carers. The
report noted that some recipients said that, without them, they would fall into poverty or would be unable to remain living at home. Receipt of DLA may be the only factor preventing the recipient from experiencing poverty.

17. DLA can act as eligibility criteria to access other benefits, and so makes an important economic difference to the recipient.

18. The draft regulations are worded so restrictively that some social care customers who have such a level of a high need that they are assessed as having critical or substantial needs under FACS eligibility, would be removed from eligibility, leaving social care services to meet the financial shortfall. The loss of DLA to those with moderate support needs erodes the preventative role DLA plays, so more people are likely to fall within these groups.

19. As it is not clear how the new criteria will be scored, it is not possible to say how many people who currently receive middle or high rate care will pass the new eligibility criteria. It is also unclear whether carers allowance will align to both of the daily living components. Consequently an assessment of the impact is hard to assess with any certainty.

20. In Lambeth, the majority of customers receive adult social care services because they are assessed as having critical or substantial care needs under FACS eligibility. We are concerned that significant numbers of these core social care clients groups will lose entitlement when PIP is introduced, due to the more stringent test that lacks the flexibilities of the previous regulations through the introduction of descriptors.

21. We are concerned that the introduction of PIP will lead to pressure on front-line social care and health staff across local government, at a time of severe economic restraint and pressure on services.

22. However we are especially concerned about those people who lose ESA because of the more stringent work capability assessment test and more stringent conditions introduced through PIP. Those with moderate conditions could find themselves denied Employment and Support Allowance because they are declared fit for work and denied PIP because they have conditions which do not lend themselves well to the assessment process or fit within the new Regulations proposed.
23. The extent to which PIP will act as a gateway to other benefits, including Carers Allowance, has important considerations on the extent to which people will be impacted by loss of DLA.

24. DLA acts as a passporting benefit for many other things, including exemption from the Single Room Rate and the benefits cap. Seeing large numbers being removed from DLA will have secondary impacts on Local Authorities through impact on housing as well as on social care budgets.

25. Loss of income to meet disability costs will lead to greater demand on care and support services, as the preventative nature of DLA is removed. The proposals, if unamended, could lead to greater poverty and a resultant breakdown of health and social functioning. The link between poverty and ill-health is well recognised, with the link between poverty and mental ill-health of particular concern.

26. It is not clear how the protection and passported benefits afforded by DLA will be carried forward when PIP is introduced. Passported benefits can often be worth more than DLA, and a loss of DLA under the Housing Benefit reforms proposed will have a devastating impact on housing costs, leading to some of those who lose DLA becoming unable to afford to sustain their tenancies.

27. As shown in the below examples, loss of DLA can have a devastating impact on family incomes. It is foreseeable that many on carers income will be forced to look for work in order to receive benefits and may not be able to continue to care.

28. Of those who lose entitlement it is not known how many will appeal and whether the tribunal system or advice sector will be able to cope with increase in demand.

29. The piloting over the summer seems to be driven by the need to reduce expenditure by 20%, and the proposals for PIP seem to have been almost 'worked backwards' from that requirement. The benefit has been made to fit the budget, not the reverse.

30. The examples in the appendix show the considerable possible financial impact on Local Authorities if PIP is lost.

Whether automatic entitlement should apply to people with some conditions or impairments and whether some people should receive awards for indefinite periods
31. From the documents provided it seems clear that the Government is keen to avoid automatic entitlement. We would however argue that, in practice, automatic entitlement can be cost effective and produce a consistent method of assessing disablement that is used effectively elsewhere in the benefits system.

32. Without automatic entitlement, for certain groups or conditions additional costs will be encountered through expenditure on face to face assessments and administration. In many cases the issue of whether a person is entitled or not should be obvious through consideration of existing social and health care reports and the assessment will be an expensive waste of resource.

The implications of a six month qualifying period

33. We have concerns about the proposal to increase the qualifying period for benefit from three to six months. Sudden deterioration in people’s illness often causes severe problems in many areas of their lives and we think they should start to receive financial help as soon as possible. The current “forward test” provision sufficiently ensures that only those with long term conditions are covered, the extension up to six months would place unnecessary burdens on those affected, including carers.

34. The extension to six months would also impact adversely on people severely disabled by chronic illness, such as cancer and those whose recovery paths may make prognosis more complex, such as stroke victims. Additional burdens are likely to be encountered as these people look to local authorities for financial support.

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

35. The proposed face to face assessment forms the cornerstone of the objective to introduce objective assessment for eligibility. However we are concerned that this will unfairly penalise people with mental ill-health or learning disabilities, whose support needs are unsuited to a snapshot medical assessment by a independent health care professional.
36. We are also concerned that other key changes including the ending automatic entitlement for certain conditions and impairments will impact adversely on these client groups. People with learning disabilities have support needs that are unlikely to change and should not be subject to regular review of all awards.

37. DWP pilots to streamline the AA and social care application processes in Islington and Greenwich in 2007-08 were encouraging. It is disappointing that there has been no recognition of the fact that existing social and health care assessments could be used to remove the need for significant numbers of claimants to undergo a face to face assessment. Such pilots have shown that such an approach can improve the targeting of the benefit and use of this information would reduce duplication and the unnecessary costs associated with the expectation that the vast majority of claimants will undergo an assessment even where detailed assessments considering similar areas of need are available.

38. The introduction of a detailed list of descriptors seems to make the eligibility more complex for those with mental, intellectual and cognitive conditions and with fluctuating conditions. The new descriptors contain words which are open to interpretation, such as ‘continual prompting’ and ‘continual assistance’, so the complexity and potential for confusion is retained.

39. The current assessment is primarily based on a lengthy claim form backed up, on occasions, by medical or social care evidence and subject to further assessment by a DWP-contracted examining medical practitioner (EMP).

40. More at odds with the notion of simplification however is the proposal that those DLA claimants who qualify at present because of their medical condition (e.g. those undergoing dialysis and people who are blind) will no longer qualify automatically and will have to go through an assessment.

41. It is important to retain principles of self assessment and a social model of disability, backed up with reports from involved and suitably qualified health and social care professionals, rather than to extend the role of medical assessments, which have always proved problematic in determining benefit entitlement.

42. Snapshot opinions from a medical viewpoint, not informed by full knowledge of the disability or even medical history, often lie at the heart of poor decision making. The
decision to replace AA with DLA was taken because of acknowledgement of the failure of such medical assessments. The problems caused by over reliance on medical assessment were also highlighted in the Harrington review.

43. The Government claims that there is no systematic way of regularly checking that an award remains correct but this seems at odds with claimant and adviser experience, as DLA claims are subject to regular and periodic reviews and reassessments. DWP’s own research into levels of payment error suggest there have been improved in accuracy levels, achieved through improved training and professionalisation of decision makers.

44. Further improvement to decision making could be achieved through additional training rather than an EMP-led ESA assessment. 39% of appeals against ESA assessments have proved successful and we would argue that this is not a model to copy.

45. The proposals will place much greater emphasis on a mandatory EMP report, similar in style (if not content) to the assessments being carried out on Employment and Support Allowance claimants. These have exceeded predictions in the higher refusal rates for that benefit.

46. Further consideration should be given to removing the need for medical assessment through sharing information between DWP and Health and Social care staff.

47. The consultation states that DLA awards can be inconsistent and unfair. Whilst the quality and accuracy of decision-making on DLA is not universally good, it is not clear how the new test would improve this.

48. There has been no evidence provided to explain how the new face to face assessment would improve decision making. The assessment procedures seem similar to the approach of ESA involving a snapshot medical assessment that has not improved decision making (especially for those with mental health and cognitive functioning and those with fluctuating conditions). This suggests the lessons from Harrington have not been learned.

49. Experience of the EMP-led ESA assessment does not inspire confidence in a more accurate system being in place for PIP. The number of ESA appeals has risen by 56% in the last two quarters and the success rate of those who are represented at appeal remains very high.
50. We would suggest that the proposals, as they stand, risk producing the poor decision making identified in the Harrington Review. If this happens large numbers of people will lose benefit unfairly.

51. The regulations place considerable emphasis on health and medication when assessing health support needs. Whilst this is unarguably important it should not be the only thing taken into consideration. For clients with mental ill-health or a learning disability, social interaction is vital to maintaining their mental health. Without taking into account factors that facilitate such interaction, clients are likely to become socially isolated and this can have a highly negative effect on their condition and development.

52. We would also argue that the vulnerability of the clients in safeguarding terms has not been sufficiently taken into account in the activities considered. It is vital that vulnerable clients are protected from all forms of exploitation.

Learning lessons from the Harrington Review

53. The scale of the migration from DLA to PIP is similar to that for ESA but it is being introduced over a much shorter period. Large numbers of people will have to be assessed over a short period, and the implications of any problems will be far-reaching with little time to put things right. People who lose entitlement and face additional costs may look to social services for increased support.

54. There should be thorough piloting to ensure that the new criteria do not exclude certain groups. We are concerned that testing on only 1000 volunteers is an insufficient pilot and would welcome the setting up an independent review similar to the Harrington review.

55. Although an appeal process is currently in place, in some areas appeals are taking over one year to be heard. The consequence for those affected can be extreme because of the impact on other benefits (illustrated in examples in appendix 1). It is vital therefore not to rush the piloting and assessment of the changes.

56. The government has stated that the payment of low rate mobility DLA to those in care homes counts as double funding. In practice there is no funding overlap as care homes take into account this income when determining the amount to charge the council.
Appendix 1
Examples of possible scenarios under PIP

Case Study 1 – family impacted

Before
- Sid and Amanda live with their 3 children.
- Amanda provides care in the home.
- Sid has brain injuries from a road traffic accident which affect his behaviour and can make him aggressive. He has problems with planning and sequencing processes.
- The family pays £300 rent pw for their 3 bed house.
- As well as £300 pw in Housing Benefit, the family also claims £390.56 in other benefits, which includes ESA for Sid, child benefit, child tax credit, carers’ allowance for Amanda and the middle rate of DLA (care) and high rate DLA (mobility) for Sid.
- The fact that Sid receives DLA means that the £500 pw benefits cap does not apply to the household.

After
- While being migrated from DLA to the new Personal Independence Payment, Sid is reassessed using the more stringent assessment process and told that his disabilities are not sufficient to merit an award of PIP. He does not share information clearly with the medical examiner, as he lacks insight into the severity of his condition.
- This decision means the family lose Sid’s DLA middle rate care component and low rate mobility component.
- It also means they now are subject to the £500 pw benefits cap.
- After paying their £300 pw rent, they now only have £200 pw to meet all their living costs where previously they had £390 pw.
- They have a £190 per week shortfall in income which they cannot meet
- The family asked to be re-housed by the Local Authority because they cannot afford the rent
- Amanda is no longer able to receive carers allowance and has to find work, but she feels unable to do so because she feels Sid cannot be left unsupervised with their children.
- The family approach children’s services for support as the loss of income has placed increasing strain on the family.
Case Study 2 – Shared Accommodation Rate

Before
- Jim is 31 and has autism.
- He is informally supported by friends/family who live in the area, so does not access council-funded services.
- He rents a one-bed private rented sector flat which costs £150 pw – this is paid by HB.
- He received DLA and also claims ESA.

After
- Jim is reassessed and is assessed as no longer being entitled to DLA.
- He is now subject to the shared room rate as he is under 35.
- He is told he now only qualifies for the Shared Accommodation Rate of £85 pw.
- He has an instant shortfall on his rent of £65 pw which he cannot make up from his personal income.
- Jim is told he cannot afford to rent a two bed in Lambeth with another adult sharer as the £85 pw Shared Accommodation rate he has available to spend is not enough to cover his half of the rent (£100 minimum).
- The family now need to be re-housed by the Local Authority
- Jim has to move to a cheaper area, away from friends/family, or share a larger property. He chooses the latter option but experiences difficulties with his housemates and suffers bullying due to his autism. His mental health deteriorates
Summary

The merits of the proposal to replace Disability Living Allowance (DLA) by Personal Independence Payments (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)\(^1\). 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, 1.25m of the grand total of 1.7m 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 support by evidence in the Sheffield Hallam 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 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\(^2\) 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 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.

Table 1: Districts with the highest and lowest ‘DLA with IB/SDA’ claimant rates, February 2008

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<tr>
<th>% of working age population</th>
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<td>Top 20 Districts</td>
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<td>1. Merthyr Tydfil</td>
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\(^2\) Pre-2009 local authority districts
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  

**Bottom 10 Districts**

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*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 is 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 twenty or thirty 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 documented⁴.

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.

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 fallback 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 £12bn 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 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 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 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 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.
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. 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, and more than 500 responses from organisations.

1 Disability Living Allowance reform, Cm 7984, December 2010.
2 A standard response was defined as two or more emails or letters that contained the same text, but were signed by different individuals.
6. The Government published its response to the consultation on 4 April 2011. 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. 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.

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

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3 Government’s response to the consultation on Disability Living Allowance reform, Cm 8051, April 2011.
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\(^5\), 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 (DLA) 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 seventy per cent of the current DLA caseload has an indefinite award\(^6\), 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 thirty per cent (February 2011).\(^7\) The total amount spent on the benefit this year is forecast to be £12.6bn.\(^8\) This is significantly higher than envisaged.

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\(^6\) DWP Ad Hoc Analysis, Analysis of Disability Living Allowance: DLA Awards; March 2011.
\(^7\) DWP Ad Hoc Analysis, Disability Living Allowance: Growth in the Number of Claimants 2002/03 to 2010/11, August 2010.
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\(^9\) and there is evidence that people awarded DLA do not fully understand the purpose of the benefit.\(^10\) For example, some 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.

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19. Independent research published by the Department in 2008 showed that there was an overall disallowance rate for DLA of 52 per cent.\textsuperscript{11} 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 fifty per cent.\textsuperscript{12}

**Why the DLA caseload and expenditure has increased**

20. The total caseload on DLA, including children and those aged over 65 has increased from 1.1m in 1992/3 to 3.2m in 2010/11. Expenditure has increased from £3.2bn to £12.3bn (2011/12 prices) during the same period. In just eight years the numbers of people receiving DLA has increased by around 30 per cent (August 2010).\textsuperscript{13}

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 £2bn in 1992 to £6.7bn 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

\textsuperscript{11} Disability Living Allowance: Disallowed claims, 2008, DWP Research report No 490.

\textsuperscript{12} http://www.publications.parliament.uk/pa/cm200910/cmhansrd/cm100322/text/100322w0009.htm.

\textsuperscript{13} DWP Ad Hoc Analysis, Disability Living Allowance: Growth in the Number of Claimants 2002/03 to 2010/11, August 2010.
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.\(^\text{14}\)

**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.\(^\text{15}\)

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 £630m was being overpaid and around £190m was being underpaid to claimants as a result of unreported changes in circumstances.\(^\text{16}\) 24 per cent of working age (16-64) DLA claimants have either not had a change to their award, or their award looked at, for a decade.\(^\text{17}\)

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 per cent) were overturned.\(^\text{18}\)

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.\(^\text{19}\)

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

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15 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.
17 DWP Ad Hoc Analysis, Analysis of Disability Living Allowance: DLA Awards, March 2011
19 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.
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 per cent lower than it would be without the reform of Disability Living Allowance (DLA), 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 per cent does not equate to a reduction in awards of 20 per cent; 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 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 (DLA) 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 (DLA) 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. Not reviewing these claims means that some

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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.21 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.

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 twelve 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 twelve 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 (DLA) 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. 22

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.

22 http://www.ceacard.co.uk
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 (DLA) 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 cases23; 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

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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 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 Organisation. 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

24 http://www.who.int/classifications/icf/en/
over-complexity and be challenging for consistency, administration and the time needed for assessments. As such the Department and Assessment Development Group\textsuperscript{25} 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.\textsuperscript{26} 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.

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


\textsuperscript{26}Ibid
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 twelve 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 twelve 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
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.27

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 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 (DLA) 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 (DLA) 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 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 (DLA) 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.

[September 2011]
### Annex 1: DLA Reform - Summary of Changes – changes marked in *italics*

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<tr>
<td>Qualifying Period &amp; Prospective Test</td>
<td>Have to have been severely disabled for 3 months and likely to be for a further 6 months.</td>
<td>Have to have been severely disabled for <em>6 months</em> and likely to be for a further 6 months.</td>
</tr>
<tr>
<td>Principal entitlement rules</td>
<td>Care needs and mobility are the measures used as proxies for extra costs.</td>
<td>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.</td>
</tr>
</tbody>
</table>
| Rates and components           | Two Components – care and mobility  
Three care rates and two mobility rates  
11 different award outcomes                                                                                                                                           | Two components – Daily Living and Mobility  
Two rates per component  
8 different award outcomes                                                                                                                                                                                                                                                   |
<p>| 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. | 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. |
| 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.                                                                              | 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.                                                                                                                        |
| Age – Over 65s                 | Claims cannot be taken after the age. Entitlement can continue after the age of 65 if already in receipt.                                                                                                                                 | No change.                                                                                                                                                                                                                                                                                |</p>
<table>
<thead>
<tr>
<th>Residence and presence/exportability</th>
<th>Disability Living Allowance</th>
<th>Personal Independence Payment</th>
</tr>
</thead>
<tbody>
<tr>
<td>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.</td>
<td></td>
<td>Habitually resident (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. The 26 out of 52 would be applied on a one off basis and not on a rolling basis. We are proposing reducing the period that temporary absence is allowed to 4 weeks, to align with ESA. Where another EEA competent state paying an equivalent benefit, PIP is not payable.</td>
</tr>
</tbody>
</table>

| 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. |
| 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 payability of both the care and mobility components after 28 days. |
| Award duration/reviews | Awards can be made for a fixed or indefinite period. Awards are not routinely scrutinised. | Awards will normally be made for a fixed period. Awards will be routinely reviewed. |
| “Deeming” provisions | Certain conditions are deemed to meet conditions of entitlement despite there being no functional limitation, e.g. severe mental impairment; severe visual impairment. | There will be no automatic entitlements to PIP, with the exception of the Special Rules for people who are terminally ill. |
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.

COSLA agree with a policy intent which aims to ensure that the support provided to help with the additional costs of living with a disability better reflects the desire from disabled people to live independent lives. However, we have concerns with the objective to cut expenditure by 20% which appears to undermine the government’s commitment to supporting disabled people to lead independent and active lives.

In many ways DLA has been successful and it is worth noting that there is much about DLA that works well. It has been argued that DLA is a complex benefit and we would concur there are improvements which could be made. For example significant resources are applied by Scottish local authorities in supporting appeals of which a significant proportion are successful. The volume of this work could be reduced by clarifying the weight different elements of information receive when considering an application. Argument has also been made which suggests that although take up has been increasing since its introduction, many people are continuing to miss out on the support DLA could provide them. Therefore we would welcome efforts to maximise public awareness of PIP as it is introduced.

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.

Local authorities in Scotland provide a range of services to people who are also in receipt of DLA. The reduction in expenditure and resultant loss of income for those currently receiving DLA will impact on the choices available to people with disabilities. At this time local authorities receive a contribution toward the cost of providing services such as Day Care, Domicilliary Care, Housing Support. The level of contribution is based on the ability to pay which is affected by the income received. A loss or reduction in support provided through DLA or PIP will impact on the ability to pay. Not only will this limit choice but it will result in income levels falling below those at which a contribution or charge is required from those who choose to use a local authority service.

The loss of income to offset the costs of providing these services will have serious implications for Scottish local authorities; which will be more severely affected than those in the rest of the UK because of the disproportionately high levels of disability in Scotland.

The impact of moving from three rates for DLA to two rates of PIP is not clear at present as further information about how those currently receiving support through DLA will be affected by the move to the entitlement for PIP; the DWP will be best placed to provide a mapping of existing claimants from DLA to PIP (although information requirements for PIP assessment might not be complete).

The key issue here is that a change of focus to those individuals with the most severe challenges in day-to-day life could signal a loss or reduction in support for those with low level needs. This might be seen as short-termist and runs contrary to recent thinking on the importance of preventative and anticipatory care recommended in the Report on the Future Delivery of Public Services by the Christie Commission.
If the support available to those with lower level needs is withdrawn and those needs then escalate dependency will increase which in turn will require a higher level of support. We are therefore concerned that the proposals will merely pass responsibility for meeting need from the DWP to local authority social work budgets, which are already under great strain.

We would like to see that the reforms ensure low levels of support are maintained in order to avoid escalation of need.

**The extent to which overlaps in funding exist, particularly with local authority and NHS funding, and including for people in residential care or hospital.**

The different concepts for the delivery, funding and payment of social care services and health services has long been a cause of tension and confusion for the general public. Without a fundamental change to these structures the best approach might be to provide better clarity about the differences in funding, which services are ‘free’ at the point of delivery, which are not and what the reasoning is behind this.

In terms of provision of the DLA mobility component for those living in care homes; our view is that this does not represent an overlap in funding. Local authorities provide funding for basic mobility needs including transport to necessary medical appointments etc and take this into consideration as part of a client assessment. They do not have sufficient funds to support additional independent social travel. Currently, the DLA mobility component provides highly valued additional support to improve quality of life and independence through enabling care home residents to visit friends and family and to travel when and where they wish; choices which we all value.

We would urge that mobility component of PIP is retained for care home residents.

**Whether automatic entitlement should apply to people with some conditions or impairments and whether some people should receive awards for indefinite periods.**

The current list of exemptions contained within DLA regulations cover fairly severe disability situations and it seems extremely unlikely that people with such conditions might fail to qualify for the revised benefit. A requirement for further assessment would appear to be an unnecessary burden of stress and inconvenience for the most vulnerable and would not seem to be an effective use of resources.

We believe it is right that people with some conditions should receive automatic entitlement and any decision to review an award should depend on the merits of each case, suffice to say that there should be an option not to review in certain cases.

**The implications of a six month qualifying period.**

Changing the ‘prospective test’ to determine whether a disability existed six months before a claim is made, and a requirement for an additional 6 month period to pass after claiming, will exclude many vulnerable groups whose conditions are severe but possibly not chronic; such as cancer sufferers.

In addition there are issues for those who undergo dialysis and those living with other conditions which incur immediate additional cost such as heating, which would not be helped by an extended qualification period. For example, those receiving chemo-therapy treatments would incur expenditure early on and there would also be early expenses associated with mobility for those who have lost both lower limbs (the needs of veterans must also be met).
So in terms of the proposed six months qualification period for PIP we suggest amending this by reducing it to three months in line with the existing qualification period for DLA. This would also ensure consistency with the qualification for other benefits like Attendance Allowance

The extent to which PIP will act as a gateway to other benefits, including Carers Allowance and the Motability Scheme.

The proposed reforms to DLA and other benefits will mean that the current criteria for access to a range of benefits will no longer exist. A complete overhaul of the rules on access to passported benefits will be needed requiring considerable administrative, policy and financial implications for councils.

The impact is difficult to assess given the range of service configurations councils have developed to meet local need. There will be a requirement for an alternative assessment procedure for services, notably applications for Blue Badges and Travel Cards. Carers will also require individual assessments for support through the Carers Allowance and consideration will be needed for how to transfer the current ‘carer status’.

There will be implications as a result of the loss of protection from non-dependant deductions and entitlement to DWP premiums. This may result in an overall loss of means-tested benefit, free school meals, clothing grants and access to the Social Fund. For example a tenant receiving HB and DLA Care with a resident non-dependent would have the non-dependent deduction reintroduced leading to an increased risk of homelessness resulting from non-payment of the non-dependent deduction.

Other indirect losses might include home visiting services for libraries, accessible bus travel and a potential impact on shop mobility; if people can't afford transport to shop demand for the shopping service will increase. Many people currently in receipt of DLA will have less disposable income leading to lower take up of other services including community alarms, health and social activities, support services, home care and gardening.

There has already been a commitment to consider existing passporting arrangements whilst developing PIP but it is difficult to see how the policy objectives for PIP can be met without moving away from the existing criteria for DLA.

We would urge the committee to ensure adequate arrangements are made to ensure the eligibility criteria for PIP can be mapped on to the existing criteria for DLA. Alternatively sufficient resources should be made available to enable Scottish councils to develop and implement new assessment procedures.

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.

In additional to the matter of passporting a number of concerns have been raised with regard to PIP assessment. At the time of writing some areas such as details about the scoring and weighting of scores against elements of the assessment criteria have not been sufficiently explained.

We note with concern that formal testing of the assessment did not include an independent day of testing run by disability organisations in partnership with DWP and that the summer testing of 1,000 disabled people has been developed without involvement of the Disability Benefits Consortium or DA. This approach appears to
undermine confidence in the willingness or capacity of DWP to include the views and experience of individuals and groups and increases fears that DWP is focussed purely on cutting DLA/PIP expenditure.

**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.

We understand that the Work Capability Assessment (WCA) is still failing to operate effectively and that there are concerns that many disabled people are not receiving essential support (including finance) to get and keep work. We would expect lessons to be learned from that experience when introducing the PIP assessment.

We also suggest that assessments must be carried out by individuals with sufficient skills and expertise appropriate to the impairment type of the claimant. Furthermore people with prescribed impairments and conditions (including severely visually impaired, severely mentally impaired, double amputee, deaf/blind and those undergoing haemodialysis) should be exempt from the assessment.

**How DLA/PIP should apply to children and people over the state pension age.**

We understand that a commitment to continue an award of PIP that has been made to a person prior to their state pension age has been made by DWP in line with the existing arrangements for DLA awards.

**The steps DWP needs to take to ensure that its reform proposals are clearly and effectively communicated to claimants and the general public.**

Concerns have already been expressed about the speed at which these major changes are being taken forward by the DWP and about the quality of engagement with appropriate stakeholders. The number of related consultations being taken forward by DWP, the UK and devolved governments on elements of DLA, and the wider welfare reform, can be described as overwhelming for all but the most well resourced of stakeholder organisations, whilst the release of detailed information can best be described as incremental.

Part 4 of the Welfare Reform Bill can be described as an enabling bill and as such anxieties arise about the ability to influence the details as they emerge once the Bill becomes an Act.

The reform of DLA raises a wide range of issues and touches on an equally wide range of areas of expertise. We believe the DWP should follow through with its commitment to fully inclusive ongoing consultation with all stakeholders. The timetable for reform needs to take cognisance of the limited capacity stakeholder organisations have to ensure properly considered contributions are made and to recognise in addition the pressures the wider work on welfare reform also requires from these organisations.

**Transitional arrangements**

Removal of entitlement will make independent living more challenging for people to achieve. Where there is any detrimental impact, there must be adequate and effective transitional arrangements and it is essential that the reform provides effective solutions.
for those disabled people who currently receive DLA but who will no longer qualify for PIP and will face reduced income.

The reform must provide solutions which enable PIP to be used as a passporting benefit and options should be examined to ensure that the financial contributions lost to LA social care services through withdrawal of DLA are recovered.

A sensible and reasonable approach must be taken in relation to any decisions on consideration of aids and adaptations as these do not completely remove the need for assistance with daily living and there can be shortages or waiting lists.

Reform also needs to establish and firmly embed effective arrangements for information sharing.
Written evidence submitted by Arthur Rucker (PIP 55)

Arthur Rucker is a volunteer benefits specialist at the Sevenoaks and Swanley Citizens Advice Bureau. This Submission expresses Mr Rucker’s personal views and not those of the Bureau.

The Government’s Green Paper and its Response to the Consultation

1. In December 2010 the Department of Work and Pensions (DWP) published a Green Paper about its proposals to replace disability living allowance (DLA) with Personal Independence Payments (PIPs). Like their predecessors, PIPs would not be means-tested. The Green Paper initiated consultation on these proposals. Mr Rucker sent comments to Citizens Advice Headquarters, which was one of the many organisations that responded to the Consultation.

2. This submission also takes account of:
   a. The Government’s Response to the Consultation published in April 2011;
   b. A Government Policy Briefing Note issued on 9 May 2011; and
   c. The Disability Alliance’s Factsheet F60 issued on 22 August 2011.

3. Other relevant enquiries are:
   a. Professor Harrington’s enquiry on the future structure and administration of employment and support allowance (ESA); and
   b. The social care study by an independent Commission on the Funding of Care and Support.

4. Mr Rucker is also aware that the Department for Work and Pensions (DWP) told Citizens Advice Headquarters last winter that it intended to reduce the current DLA budget by 20%.

The Government’s policy

5. The Government is committed to PIPs replacing DLA for working-age claimants in 2013/14.

6. Very sensibly, the Government wishes to build up experience with PIPs for working-age adults before it extends PIPs to children.

7. The Government has not yet announced any plans to replace attendance allowance (AA) for the over-65s, but it has said that:
   a. Those receiving PIPs before they reach 65 will be able to keep it afterwards (as is the case with DLA at present); and
   b. It will consider whether to raise the age at which people have to claim AA rather than PIPs in line with the state pension age.

While the two last ideas are welcome, the injustice of providing a much less valuable benefit for those aged over 65 will need to be addressed before long.
8. Simplifying pretty grossly, the main similarities and differences between PIPs and DLA will be as follows:

9. Like DLA, PIPs will have two components:
   a. A “daily living” component (somewhat similar to the DLA care component but with some important differences); and
   b. A “mobility” component (similar to the DLA mobility component, but again with important differences).

10. As with DLA, there will be two rates of the mobility component – but they may well be composed differently. Although the DLA care component has three rates, present plans are for the daily living component to have only two rates.

11. As with DLA (and AA), PIPs will be cash payments, which the recipients will be free to use as they wish. They will provide a cash contribution towards the additional costs that disabled people face, so as to enable them to lead as full and active lives as possible. Like DLA, PIPs will be non-means-tested and non-taxable.

12. The daily living component assessment will be based on claimants’ ability to carry out a number of activities – probably (1) planning and buying food, (2) preparing and cooking food, (3) feeding and drinking, (4) managing medication and monitoring health conditions, (5) managing prescribed treatment other than medication, (6) washing and grooming, (7) toileting and managing incontinence, (8) dressing and undressing and (9) communicating with others.

13. The mobility component assessment will be based on claimants’ ability (1) to plan and follow a journey and (2) to move around (including moving around in a hand-propelled wheelchair).

14. The qualifying period will be extended. Claimant will need to have had the disabling condition for six months before PIP can be paid, as compared with the present three months for DLA but in line with the present six months for AA. As with DLA (but not AA), claimants must expect their condition to continue for six months after claiming. As with DLA and AA, there will be an exception for those who are terminally ill.

15. While decision-makers will continue to take account of evidence from GPs and hospital specialists, nearly all PIP claimants will have to undergo face-to-face assessments by DWP-nominated health care professionals (not necessarily doctors).

16. No PIP awards will be made for indefinite periods; and all DLA recipients, including those awarded DLA for an indefinite period, will have their cases reassessed. Again, there will be an exception for the terminally ill.

17. As with DLA, people in care homes who do not pay for their care will not be eligible for the PIP daily living component. The Government’s decision that they should continue to be eligible for the PIP mobility component is most welcome.

18. Important decisions on passporting from PIPs to other benefits (such as carer’s allowance and disability premiums) will have to await the Government’s decisions on the new “universal credit” (which will replace all the present means-tested benefits).
**Comments**

**Cost**

19. It is impossible to say anything constructive about PIPs without taking account of the Government’s intention that they should be 20% less costly than DLA. The Government should be asked to explain how they think a 20% saving can be achieved - RECOMMENDATION 1.

20. The DLA care component provides useful additional income when the claimant’s carer is a spouse (or another family member or friend) – especially when the carer can also claim carer’s allowance. However, it makes only a minimal contribution when the claimant has to pay for professional care.

   a. The conditions for the highest rate are extremely strict: the claimant must need continual supervision or frequent help with bodily functions *throughout* the day and help at least twice during the night.

   b. In most parts of the country, the highest rate of the care component would probably pay for a professional carer to be in the claimant’s house for about one day a week. So in reality professional care is means-tested.

   It seems inconceivable that any money can be saved over genuine daily living component claims. Indeed some of the Government’s ideas (the very welcome proposal to include food-shopping in the assessment, for example) look likely to increase rather than to reduce costs.

21. The DLA mobility component is also useful – especially the higher rate with the access it gives to Motability cars, disabled parking badges and exemption from vehicle excise duty (VED). However, the most frequently used condition for the higher rate – “virtual inability to walk” – is far too strict and excludes many people whose mobility is seriously restricted.

   a. Hopefully, the new conditions will be less restrictive; and, if so, this will increase costs.

   b. The new conditions will exclude wheelchair-users who can mobilise over the required distances.

   c. The 20% savings figure may have included the removal of the mobility component from those in care homes, an idea now thankfully abandoned.

   It is certainly not obvious that there is much scope for overall savings on genuine mobility component claims.

22. There are signs that the Government may be thinking of reducing the cost of DLA in a number of other ways, such as:

   a. Making the conditions for PIPs even tighter than those for DLA (hopefully this is not intended);

   b. Having only two rates of the daily living component;

   c. Excluding anyone who will not have the disabling condition for one year;

   d. More frequent reassessments; and

   e. Reducing the costs of administering the benefit (including the costs of the appeal process). These costs must be very high – and will be further increased by the involvement of DWP-nominated health care professionals in the assessment
process. The Government should be asked to publicise its administrative costs and how it has in mind to reduce them.

It would be hard to object to saving money through more frequent reassessments (provided that these are done sensibly and humanely) or through administrative efficiencies (provided that the DWP keeps sufficient front-line staff to administer the benefit effectively). Indeed, there could well be scope for reducing duplication of care needs assessment between the DWP and local authority social services departments. However, there would be serious objections to the other three measures (see below).

The daily living component

The number of rates

23. The Government has not yet explained exactly how it will reduce the number of rates from the three DLA care component rates to the two PIP daily living component rates. All that it has said is that the higher PIP rate will be no less than the highest DLA rate. If the intention is to pay the higher PIP rate to those who currently qualify for the DLA middle rate, the change would be most welcome. However, there are fears that:

a. The DLA lowest rate will be eliminated, denying benefit to people who cannot cook a main meal for themselves or who need help for a significant part of the day (as distinct from frequently throughout the day); or

b. People now eligible for the DLA middle rate will only qualify for the PIP lower rate: these are people who need a great deal of help in the day or in the night but not in both.

24. Neither of these changes would be acceptable.

a. Eliminating the lowest rate would remove exactly the kind of help that many people actually need, including the relevant passported benefits. Hopefully, this is not intended. The Green Paper shows that 880,000 claimants would lose out (assuming that they all have good claims).

b. Paying only the lower PIP rate to those now qualifying for the DLA middle rate would not reduce their benefit significantly and would also remove the important passported benefits associated with the middle rate. The Green Paper shows that 1,600,000 claimants would lose out (again assuming that they all have good claims).

25. The Government has said that two PIP rates would be fairer, more straightforward to administer and easier for individuals to understand. It is hard to see why they would be fairer. As to ease of understanding, this Citizens Advice Bureau has experienced no problems in explaining the three rates to clients (unlike ESA and tax credits, which cause rapid glazing over of the eyes).

26. Unless the Government can undertake that the vast majority of those who currently receive the middle rate of the DLA care component will in future receive the higher rate of the PIP daily living component, it should be pressed to retain three rates – RECOMMENDATION 2.

The statutory descriptors

27. The Government has proposed a new approach to the daily living component assessment. A points-based assessment of claimants’ ability to perform specific activities will replace the old attempt to measure how often and for how long claimants
need help with their bodily functions. On the whole, this is a welcome change. However, its success will depend on the statutory descriptors that will be used. Full comments on the list in the Disability Alliance factsheet must await the Government’s proposals on (1) the points to be awarded to each descriptor and (2) the number of points required to qualify for the two (or three) rates of the daily living component. However, the following comments are offered at this stage.

28. **The descriptors are quite complicated.** Some might say this will not matter, as claimants do not need to understand the wording of statutory instruments. However, that thought would be wrong. If decisions are based on whether claimants fall within specific descriptors, those descriptors must be set out in the claim form. Failure to do so will lead to the kinds of problems that have been experienced with the ESA limited capability for work questionnaire - where (for example) claimants are asked to say whether they can move 50 metres (15 points if they can not) or 200 metres (6 points if they can not) but not 100 metres (9 points if they can not). It is not easy to expressing statutory descriptors in simple language, but the attempt must be made to do so.

29. There do not appear to be any descriptors relating to getting in and out of bed. These should be included.

30. There do not appear to be any descriptors covering moving around the house, sitting and rising from a seat or going up and down stairs. These should be included.

31. The toileting descriptors do not distinguish between day and night. Quite a number of this CAB’s clients can manage their toilet needs in the day but need help with them during the night. This distinction should be made.

32. The physical health descriptors appear not to provide for those who can perform the various activities but who would take an unreasonably long time to do so if they had no help with them. This aspect should also be covered.

33. The inclusion of food-shopping is most welcome. Cleaning the house (a huge problem for many disabled people) should also be included.

34. **The mental health descriptors** appear to be confined to problems with communicating with others. Other conditions, such as acute depression, anxiety or panic attacks, do not appear to be covered. These conditions may well require help from a carer, for example to comfort and calm the claimant or to encourage the claimant to get out of bed in the morning. The mental health descriptors should be expanded.

35. These comments may point to a possible weakness in the Government’s approach to the daily living component. While it is right to focus on the help disabled people need to live as normal a life as possible and (where possible) to get out of the house and go to work, it should not be forgotten that a large number of disabled people need help from a carer (whether a professional, a family member or a friend). Some people will find it sufficient to have a carer coming in once a day, but others will need a carer in the house for a large part of the day and/or night. This very basic need must not be overlooked.

36. **The daily living component statutory descriptors need to be sufficiently comprehensive to include the main aspects of care covered by the DLA care component (as well as some new activities); but they also need to be expressed in language that is sufficiently simple to be reflected in the PIP claim form – RECOMMENDATION 3.**
The mobility component

37. Hopefully, the two rates of the mobility component will allow the lower rate to be paid to those who would not now qualify at all for the DLA mobility component.

38. The first of the proposed mobility descriptors, which would presumably score no points, is that the claimant can move at least 200 metres unaided or with the use of a manual aid (defined as including a walking stick but not a wheelchair). Hopefully this would mean that any claimant who can not move 200 metres – or who would take an unreasonable time to cover that distance – would qualify for the lower rate of the mobility component (which at present is for those who can walk but who need supervision and guidance when outdoors). If so, this would be a most welcome change. It would be especially welcome if the lower rate in future allowed access to passported benefits such as Motability cars, disabled parking badges and exemption from VED.

39. It looks as if the higher rate of the mobility component will still be built around the inability to move 50 metres. If this is the case:
   a. The descriptor should include those who can move this distance but who take an unreasonable time to do so (as the DLA descriptor does).
   b. 50 metres is a very short qualifying distance. The benefit would be a great deal fairer if it could be extended to 100 metres.

40. The lower rate of the PIP mobility component should be available to people who cannot move 200 metres at a reasonable speed on level ground without stopping or severe discomfort; and, if at all possible, those who cannot move 100 (rather than 50) metres in this way should qualify for the higher rate – RECOMMENDATION 4.

Aids

41. The Government has recognised that there are problems with assessments assuming the use of relevant aids. However, it has made clear that their use will be assumed. On the whole, the Government’s approach to this issue seems about right. However:
   a. Care must be taken not to assume that claimants will have aids that they cannot afford to buy. The idea of PIPs including an up-front payment that could be used to purchase a relevant aid looks like a good one.
   b. It is also important not to expect the use of aids that would be offensive to a disabled person’s dignity – such as expecting a male claimant to use a bottle in bed at night in order to avoid the need to go to the toilet.

PIP assessments should only assume that aids will be used when (1) it is reasonable for claimants to use them, (2) the claimants are provided with or enabled to buy the aids and (3) their use would not be offensive to the claimants’ dignity – RECOMMENDATION 5.

The qualifying period

42. At present the qualifying period for DLA is nine months. There is a “backwards test” requiring the claimant to have had the disabling condition for three months before claiming; and there is also a “forwards test” requiring the claimant to show that s/he is
likely to have it for six months afterwards. For AA the “backwards test” is six months, but there is no “forwards test”.

43. The Government is proposing that both the PIP “backwards” and “forwards” periods should both be six months. This change would reduce costs but would have worrying consequences:

a. When people first become disabled, they need help straightaway (or at least as soon as they come out of hospital). Some would have huge problems if they had to wait six rather than three months before they could claim\(^2\). The Government has said that other sources of help are available during this period: it should be pressed to spell out what these are.

b. Doctors often find it very difficult to predict when disabled people will recover sufficiently to manage for themselves. The present six months forwards test could deny DLA to people who might later be found to have needed it\(^3\).

44. It looks as if the Government has decided on a six-months backwards test, despite the disadvantages that respondents to the Consultation have pointed out. If this is so, the change should be balanced by reducing the forwards test to three months – RECOMMENDATION 6.

The assessment process

45. A fairly small number of widely reported cases give the impression that there are large numbers of disability benefits cheats. This is unlikely to be true. There are some cheats - and some who receive incorrect payments innocently. However, the denial of DLA / AA to people who need them seems a much bigger problem.

The assessment by a health care professional

46. While it may appear reasonable to require DLA claimants to undergo a face-to-face assessment by a DWP-nominated health care professional, experience with similar ESA assessments is most discouraging.

a. The number of doctors and nurses available to conduct assessments of this kind must be quite limited; and the Government should certainly be asked whether it is confident of being able to find sufficient well-qualified professionals to carry out these assessments in a manner that will not attract a great deal of public criticism.

b. ESA claimants have to travel to an assessment centre (often a long distance away), where they have a 20-30 minute examination by a doctor or nurse who knows nothing about them and who does not even have access to their medical notes. Citizens Advice Headquarters said recently that 40% of ESA appeals are succeeding at present – 70% when the appellant is represented professionally.

A great deal of thought is needed before it is decided to extend this system to PIP claimants.

47. An alternative approach would be to rely on GPs or consultants - or even maybe independent assessors attached to the new large practices – to assess their patients’ PIP claims. They could be asked to endorse PIP claim forms to say whether their patients’ statements about their problems with the relevant activities were consistent with what they knew about their condition. GPs might not wish to do this, but it is hard to see
how anyone else could do it better. No doubt some spot checks would be needed to make sure that common standards were being followed.

48. However, before such a procedure could be set up, some way would have to be found of improving the quality of GPs’ reports. Many GPs (and consultants) take a great deal of care over reporting on their patients’ care and mobility problems. However, there are far too many inadequate reports.

49. The Government should defer a decision on requiring PIP claimants to have face-to-face assessments by DWP-nominated Healthcare professionals until Professor Harrington has reported on the similar ESA assessment process; and it should look instead for much better reports from GPs and consultants. The Select Committee should seek the views of the British Medical Association on these issues – RECOMMENDATION 7.

More frequent reassessments

50. While it is entirely understandable that many current DLA recipients are worried about having to be reassessed, there can be no real objection to this requirement, which could go a long way towards alleviating public concern. However, the process needs to be fair and humane (especially when it is clear that there is no real prospect of any improvement in the claimant’s condition.

51. However, it would be wrong for those whose benefit was stopped to have to wait several months for an appeal to get it replaced.

52. Anyone who has his/her DLA withdrawn and who decides to appeal or to ask for the decision to be looked at again should have his/her DLA restored until the outcome is known – RECOMMENDATION 8.

Attendance allowance

53. Whatever other changes are made, the discrepancies between AA and DLA must be addressed very soon.

   a. It is wrong to deny people help with their mobility problems just because they are aged over 65.

   b. It is also wrong to deny help to older people who need care for a significant portion of the day or who cannot prepare a cooked main meal for themselves. This is just the kind of help that many older people are most likely to need, if they are to continue living in their own homes.

   c. The Government has argued that disabled people aged under 65 are at a greater disadvantage in providing for the disabilities that we must all expect in our old age. However, this argument is specious. There are many reasons why people find it hard to provide for their old age, of which disability is only one.

   d. If the lack of adequate support for older people living in their own homes drives them into care homes, the overall cost to the State is likely to be higher.

54. As soon as resources permit, PIPs should be extended to all qualifying over-65s - RECOMMENDATION 9.
Summary of recommendations

55. It is recommended that:

RECOMMENDATION 1. The Select Committee should ask the Government to explain how they think a 20% saving can be achieved through the reform of DLA (paragraphs 19-22).

RECOMMENDATION 2. Unless the Government can undertake that the vast majority of those who currently receive the middle rate of the DLA care component will in future receive the higher rate of the PIP daily living component, the Select Committee should pressed for the retention of three rates (paragraphs 23-26).

RECOMMENDATION 3. The daily living component statutory descriptors need to be sufficiently comprehensive to include the main aspects of care covered by the DLA care component (as well as some new activities); but they also need to be expressed in language that is sufficiently simple to be reflected in the PIP claim form (paragraphs 27-36).

RECOMMENDATION 4. The lower rate of the PIP mobility component should be available to people who cannot move 200 metres at a reasonable speed on level ground without stopping or severe discomfort; and, if at all possible, those who cannot move 100 (rather than 50) metres in this way should qualify for the higher rate (paragraphs 37-40).

RECOMMENDATION 5. PIP assessments should only assume that aids will be used when (1) it is reasonable for claimants to use them, (2) the claimants are provided with or enabled to buy the aids and (3) their use would not be offensive to the claimants’ dignity (paragraph 41).

RECOMMENDATION 6. If the “backwards test” is increased to six months (regrettably), that change should be balanced by reducing the forwards test to three months (paragraphs 42-44).

RECOMMENDATION 7. The Government should defer a decision on requiring PIP claimants to have face-to-face assessments by DWP-nominated Healthcare professionals until Professor Harrington has reported on the similar ESA assessment process; and the Government should look instead for much better reports from GPs and consultants. The Select Committee should seek the views of the British Medical Association on these issues (paragraphs 46-49).

RECOMMENDATION 8. Anyone who has his/her DLA withdrawn and who decides to appeal or to ask for the decision to be looked at again should have his/her DLA restored until the outcome is known (paragraphs 50-52).

RECOMMENDATION 9. As soon as resources permit, PIPs should be extended to all qualifying over-65s, replacing attendance allowance (paragraphs 53-54)
CASE NOTES

1. Several male clients appealing against the refusal of DLA have been asked at the hearings whether they could use a urine bottle at night or take no drink several hours before going to bed, in order to avoid the need for help to go to the toilet. These questions were put to a Moslem client, for whom any spillage of urine would have been especially offensive.

2. This Bureau has had several working-age clients in the West Kent Neurological Rehabilitation Unit who have had a sudden severe stroke or a serious motor accident. Suddenly, a settled way of life has been turned upside down. Mortgage commitments, etc, do not go away; and expensive arrangements are often needed when the clients come out of hospital (and this could be well under six months after they went in). Quite often, the doctors find it hard to predict their patients’ condition six months after claiming.

3. One client’s GP wrote “not known” against the DWP’s questions about self-care and mobility. He had refused the client’s request for an appointment to talk about his care and mobility problems. Another client suffers from a condition causing severe pain. He was refused DLA after an unsatisfactory report from his consultant. Although this consultant told the client that he was having the only available treatment and could expect no improvement in his condition, he did not reply to the DWP’s questions about care and mobility and wrote that the prognosis was “good”! The same client’s young GP was willing to write a helpful letter until a more senior colleague told her that it was not a GP’s job to write letters of this kind. Despite this, she was subsequently persuaded to write a helpful letter; and the client’s appeal then succeeded.
Written evidence submitted by Professor Roy Sainsbury, Social Policy Research Unit, University of York (PIP 56)

Introduction

1 In 2008 the Social Policy Research Unit 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.

2 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


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 £2bn 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**, i.e. 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**, i.e. 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**, i.e. 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
• 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
• 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.

References


