Executive summary
About the Disability Benefits Consortium
The Disability Benefits Consortium (DBC) is a national coalition of more than 80 different charities and organisations committed to working towards a fair benefits system. Using our combined knowledge, experience and direct contact with millions of disabled individuals and carers, we seek to ensure that Government policy reflects and meets the needs of all disabled people.

About the research
Personal Independence Payment (PIP) is a source of financial support designed to help disabled people and those with long-term conditions manage the extra costs of their condition. It was introduced in 2013 to replace Disability Living Allowance (DLA) with a view to “focus support on those with the greatest need”¹.

The Department for Work and Pensions (DWP) has commissioned two independent reviews into the implementation of PIP over the last five years. However, there has never been a detailed examination of how effectively PIP is working overall and, crucially, whether it is meeting its policy objectives. With no further reviews to come, this report is the first detailed opportunity to evaluate PIP as a whole.

In order to examine how well PIP is operating for disabled people and those with long-term conditions, the DBC and its members conducted a survey of 1,730 PIP claimants. We have also pooled DWP statistics and DBC member organisations’ own research and insights to contextualise these findings.

It’s clear that extra-cost benefits can make a huge difference to the lives of disabled people and those with long-term conditions. However, there are significant problems with how PIP works and is operating. These problems are increasing stress and anxiety among claimants and are often preventing people from getting the support they need.

For many people, PIP simply isn’t working.

Research findings
Submitting a claim for PIP is extremely difficult and providing supporting evidence is a struggle.

- Over 70% of respondents found the PIP application form ‘hard’ or ‘very hard’ and 11% of respondents were unable to complete it at all.

- Almost 60% of respondents found providing supporting evidence ‘hard’ or ‘very hard’.

The stress and anxiety of undergoing PIP assessments is making people’s conditions worse.

- Almost two-thirds of respondents to our survey disagreed when asked if assessors understood their condition.

- Almost 90% of respondents described their assessment as ‘stressful’.

- Over three-quarters of respondents agreed that the stress and anxiety associated with their PIP assessment had made their condition worse.

The PIP assessment criteria are preventing people from getting the support they need

- Evidence from DBC organisations has consistently shown that the assessment criteria continue to fail to account for fluctuation, and changes to the mobility criteria have seen many people with significant need lose out on support.

- Restrictions to the criteria have been proposed by the Government in a haphazard fashion since 2013 without clear evidence, an underlying strategy or significant input from disability charities.

Disabled people aren’t receiving the right level of financial support under PIP to manage the extra costs they face.

- Over half of respondents disagreed when asked if they thought they were awarded the right level of financial support. Of those respondents who had seen a copy of the PIP report completed by their assessor, 64% felt it ‘badly’ reflected the answers given during their assessment.

DWP data shows that almost half (48%) of those who have already been reassessed from DLA to PIP have either totally lost their award or received a reduced award to date. 40% of people who told us they had lost access to their Motability car explained that they could no longer get around independently. 44% were forced to buy their own car and 31% were forced to pay for taxis, with consequences for their ability to get out and about.

The numbers of PIP claimants seeking to appeal their decisions are increasing exponentially and the majority of these appeals are successful.

- PIP appeals now comprise 45% of the Social Security and Child Support (SSCS's) 228,000 total tribunal receipts in 2016/17.
- In 2013/14 the proportion of successful PIP appeals stood at 26%. In the fourth quarter of 2016/17 this increased to 64%.

Gaining access to PIP benefits people significantly, but losing access to extra-costs support has damaging consequences.

- 58% of people who had gained support under PIP explained that it enabled them to buy the extra things necessary to carry out daily activities independently, while 32% of respondents reported an improved relationship with family members, their spouse or carer.

Recommendations
PIP is not fit for purpose in its current form. It requires significant, urgent improvement to restore fairness and disabled people’s confidence in the system. The DBC recommends the following changes:

Application process
1. The DWP should immediately introduce simplified claim forms that are readily available in Jobcentres, downloadable online and in accessible formats (such as audio described and easy read), without the need to return them within four weeks.

Evidence gathering
2. The DWP should commission an independent review of the evidence gathering processes, to explore ways to:
   - educate health and social care professionals on how to provide relevant supporting evidence
   - ensure duties and responsibility of the assessor, the DWP and claimant are clear and observed
   - make sure the DWP has a strategy to articulate to claimants what evidence will be most useful for their claim
   - ensure evidence supplied by friends and family members is given due consideration
3. In order to restore confidence in the process, assessors should be obligated to review all supporting evidence provided by a claimant, with penalties if they do not.
Assessments

4. A thorough review of the PIP assessment criteria should be urgently conducted, with meaningful involvement from disabled people and those with long-term conditions to ensure criteria are fair and truly reflect the extra costs that people face. In particular, this should focus on examining rules setting out how fluctuation is considered.

5. Restore the ‘20-metre rule’ for enhanced mobility support to 50 metres.

6. The DWP must re-establish direct responsibility for assessment quality and publish an urgent quality improvement plan to ensure assessment companies are conducting assessments consistently and to a high standard.

7. Reverse the changes made earlier this year to the mobility criteria, which restrict the ability of an individual who experiences overwhelming psychological distress when planning and executing a journey to qualify for PIP.

Appeals and awards

8. Pay PIP claimants an ‘assessment rate’ during the lengthy appeals processes, as is the case with Employment and Support Allowance, to enable them to maintain their independence.

9. Regularly publish data on the average length of time Mandatory Reconsiderations are taking and detailed information on how people are qualifying for PIP.

10. Introduce indefinite PIP awards for people with severe, complex conditions that have no prospect of improvement or are progressive. If reassessments absolutely must be undertaken because additional support may be available, these should happen without the need for a face-to-face assessment.

To find out more, please visit parkinsons.org.uk/pipreport