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# Ten Years of PIP

## A decade-long mistake?

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Written by Abby King  
on behalf of Reading  
Welfare Rights

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Registered Company  
Number: 3626105



# Executive Summary

An 84% failure rate in any area of work is an absolute catastrophe. How, then are we expected to let it slide when it applies to a Government department?

Between April 2013 and September 2022, 1.1 Million people challenged the DWP for either awarding them no support or insufficient support to cope with their long-term illnesses. 231,000 of these people's awards were then changed after they complained to the DWP. However, 407, 000 other claimants still took DWP to a benefits tribunal to challenge their lack of support. In 65,120 cases, the DWP admitted that their decision was wrong and changed it in the claimant's favour before it could be heard by a judge. A further 276,760 appeals were overturned in the claimant's favour by the benefits tribunal. Therefore, 84% of DWP's decisions to not support vulnerable people were unlawful.

Reading Welfare Rights CEO, Matt Harrison, responds to this data:

*"If 84% of Heinz Baked Beans cans failed the quality control test, Heinz would soon go out of business. If any employee made mistakes 84% of the time, they'd soon be dismissed - but because it's a Government department assessing people who are unwell and often impoverished, this disgraceful ten-year record of failure is brushed under the carpet by the Government."*

A decade on from the introduction of PIP after the Welfare Reform Act of 2012, Reading Welfare Rights want to hear first-hand from claimants. Our clients tell us every day how humiliating, intrusive and traumatic the process applying for PIP is. After ten years of hardship, isn't it time the Government started listening?

A humane approach to welfare begins by recognising the most vulnerable members of society and devising a system enabling them to express their needs with dignity. We want to know a) is the application process accessible to those who need it, b) how relevant the assessments are to the outcomes and c) the barriers to claiming.

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# Introduction

The Welfare Reform Act of 2012 was a major overhaul of the benefits system. It saw the introduction of Universal Credit as well as the abolition of Disability Living Allowance (DLA) for people of working age, and, in its place, Personal Independence Payments (PIP). As with its predecessor, PIP is a benefit for those with long term health conditions and is not means-tested, meaning one's financial situation is not taken into account. The graphic below shows the legal definition of PIP.

The Coalition Government rationalised the change to the system by saying the previous system was too complicated and confusing:

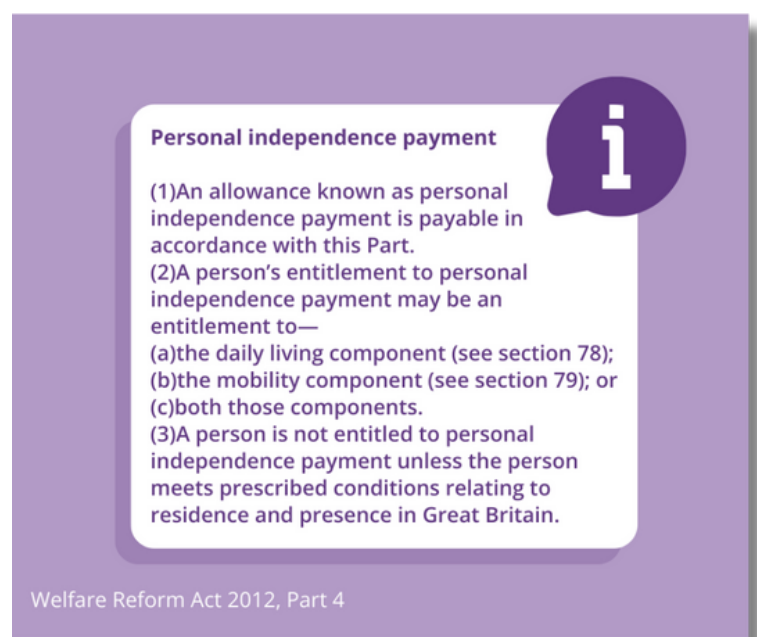
**'The government believes that:**

- the current system is too complex
- there are insufficient incentives to encourage people on benefits to start paid work or increase their hours

**We are aiming to:**

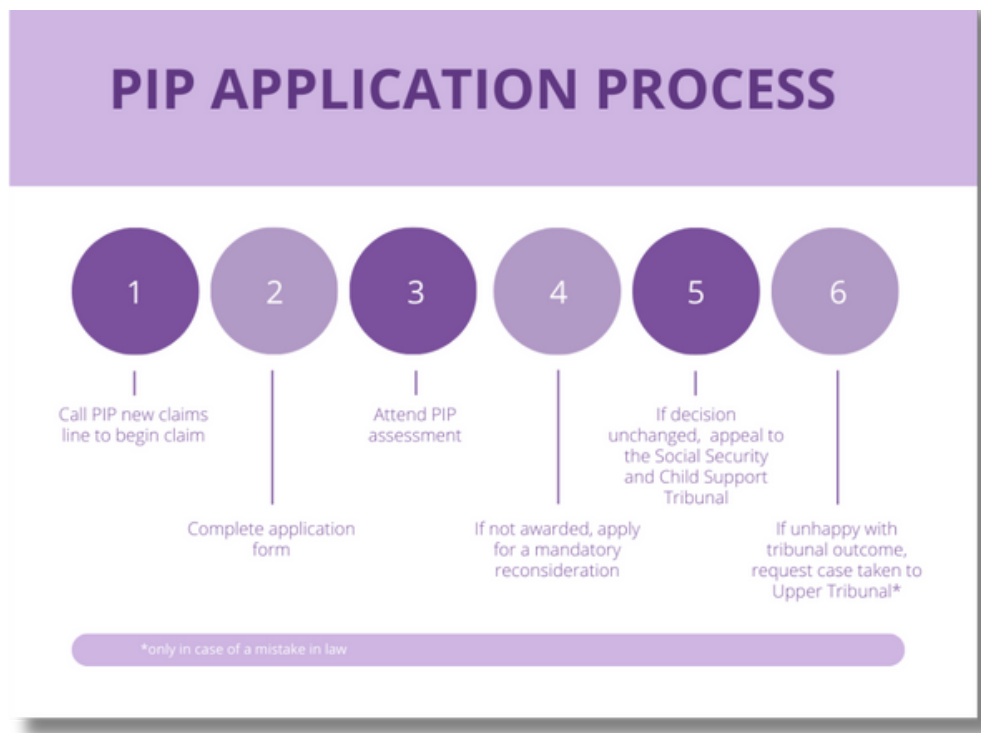
- make the benefit system fairer and more affordable
- reduce poverty, worklessness and welfare dependency
- reduce levels of fraud and error'[1].

Personal Independence Payments went live from 8 April 2013. PIP was designed to be 'a more sustainable benefit and make sure support continues to reach those who face the greatest challenges to taking part in everyday life'[2]. There was in reality very little change. Both PIP and DLA assess claimants' needs in terms of daily living and mobility. The only major difference between the two is that PIP has awards periods and reviews. The Welfare Reform Act sets this out: 'An award of personal independence payment is to be for a fixed term except where the person making the award considers that a fixed term award would be inappropriate'[3].



# Introduction

In practice, PIP is no less complicated than its predecessor. The process from initial application to eventual award is long, complex, and unnecessarily difficult to navigate. The diagram below shows the application process, from start to finish.



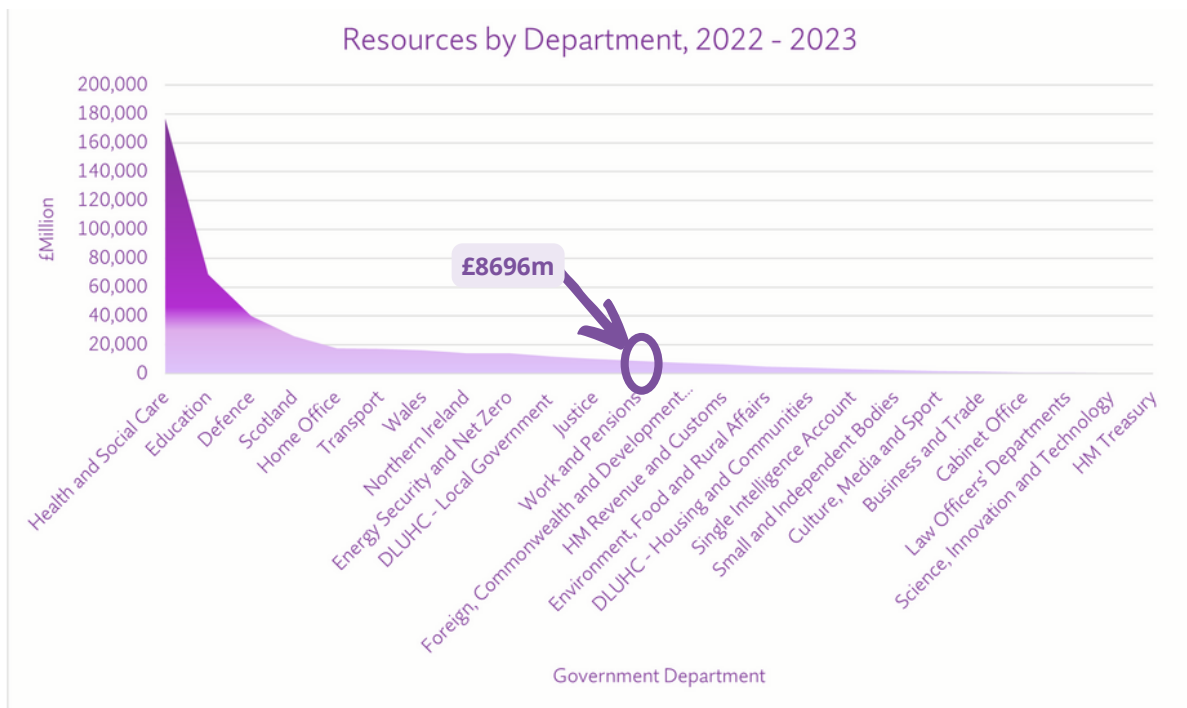
Claimants must begin their claim by telephoning the new claims line, this then triggers a form known as the 'how your disability affects you form', referred to in this report at the application form. The claimant has one calendar month to complete the form and return it. An appointment is then booked with the claimant and a health professional, justified by the DWP as 'evidence gathering'. These assessments will be looked at in further detail in the course of this report.

If the decision made after the assessment does not go in the claimant's favour, there is a one month period in which to submit a Mandatory Reconsideration, which is asking the DWP to look at the decision again. If the result remains unsatisfactory, the claimant moves on to the appeal stage, where they have the opportunity to argue their case before a tribunal, made up of three people including a judge and disability expert. The case can be taken to the Upper Tribunal only in the case of a mistake in law.

# Introduction

The move was a push to save money. In real terms, spending on social protection was £240.5 billion in 2011-12, the greatest spend as a percentage of GDP of all public services[4]. Social protection is 'concerned with protecting and helping those who are poor and vulnerable, such as children, women, older people, people living with disabilities, the displaced, the unemployed, and the sick'[5]. The annually managed expenditure on social security benefits within this category, was £170,791 million in 2011-12[6]. After the first cases of PIP were introduced in April 2013, this rose to £178,332 million[7].

Ten years on, in 2023, the latest stats show that the spending on social security benefits from 2022 – 2023 was £246,311 million[8]. Social protection remains the function with the largest spend in public sector spending[9]. However, Government spending by department on the DWP remains low, at 1.91% of all departmental spending. The table below shows the distribution of departmental spending in 2022/23.



# Introduction

We know that there is an overlap between social security and other sectors such as health and the economy. The poorest in society are more likely to be in worse health overall than those on higher incomes[10]. It follows that the more money you spend helping those on the lowest incomes, the healthier they will be and the more they can contribute to the economy. We know it is morally correct to provide support to those who need it, but looking at it purely in economic terms, it makes financial sense too. A paper entitled 'The cost of not getting Personal Independence Payment decisions right first time' by Pro Bono Economics found that errors in DWP decision making at the assessment stage amounted to 'an estimated £23-31 million of administrative waste in the DWP itself'[11]. PIP is set out to provide resources to cover the high costs that individuals with disabilities and health conditions face, if these costs are not funded by a correct PIP decision, the costs fall onto the NHS and the social care sector. We know the cost of care is astronomical. Pro Bono Economics estimate that 'if a claimant had to resort to additional social care support for the full duration of a 38 week-long appeal (including the 7-week MR time), it would cost around £30,000'[12].

This paper is fundamentally setting out to understand the experiences of claimants. We have our own thoughts from working in this sector, but we cannot truly grasp the extent of the impact of Government policy in this area without speaking with those who are affected by it on a day-to-day basis. There is still stigma that surrounds the benefits system. A report by Turn2Us suggests that benefits claimants are the group most likely to stigmatise themselves by being concerned with how others view them and, when it comes to disability benefits, it is not always straightforward to assess 'the deservingness of others from casual acquaintance'[13] due to fluctuating conditions or invisible illness. For PIP, this is made even more tricky with the way the claimants are assessed. Unless you are an expert in a claimants condition, when you cannot physically see how it presents, you cannot make a fair judgement on how it affects them. The system is not fit for purpose.



# Client Story A



Not being awarded a PIP has made their situation much worse in a cost-of-living crisis and made their mental ill health worse due to money worries. They were not looking to get rich quick, just to manage with essentials.

Declining a PIP is not a triumph for my colleague with all their difficulties. **It is a disaster.**

In-work benefits are needed, because, under the current government, **work does not pay.** Work pay is not adequate for essentials and certainly not for any so called extras like using a local leisure centre.

It will take a long time, owing to their disabilities, for this person, to get any further up the career ladder. and have a chance to pay all bills without concerns.



# The Problem with PIP

To narrow the scope of our research, we have identified what we believe the six key problems with PIP in its current form are. These are set out in the graphic below.



## Application Stage

Being on the frontline of the welfare benefits advice sector, we know that there are deeply rooted issues with how disability benefits claimants are treated straight off the bat. In our survey of PIP claimants, we asked participants what they identified as barriers to claiming PIP. One respondent replied: 'the *[How your disability affects you]* form seems designed to be confusing and complicated and not designed for the people it is supposed to help'[14]. The form is 50 pages long which is daunting for anyone, let alone someone who is vulnerable and already struggling. It is designed to trip a claimant up and is almost impossible to fill in without assistance from an advisor.

# The Problem with PIP

As a welfare benefits charity, we would never advise a client to fill out the form by themselves, regardless of perceived competence or motivation. It is simply impossible to fill in the form without mistake when you are doing it yourself. We often say that we could not even submit our own PIP claims, due to the emotional attachment you have to your own conditions. It needs at least a second pair of eyes to complete the form. In our survey, almost 70% of respondents said they had help filling out the form, or would if they did it again[15].

The issue is not just the length of the form, it is the way it is set out. Health conditions aren't black and white and symptoms can fluctuate. For many who have lived with a condition their whole lives, or for a significant amount of time, the symptoms become almost routine, and it is hard to imagine living without them. Trying to convey this information in black and white, is not easy. This is made even more difficult when you do not know how the form is being marked.

PIP is assessed via a points system, but this is not made readily available to claimants. It was left to the voluntary sector to provide. Citizens Advice published their own table of activities, descriptors and points which can be readily accessed on the internet[16]. We believe claimants should know what marking scheme they are being assessed against. Guidelines set by the Parliamentary and Health Service Ombudsman set out best practice for public bodies which can be seen below:

**Good administration by public bodies means:**

1. Getting it right
2. Being customer focused
3. Being open and accountable
4. Acting fairly and proportionately
5. Putting things right
6. Seeking continuous improvement

Parliamentary and Health Service Ombudsman

Under the heading 'being open and accountable', the advice is that 'they [public bodies] should state their criteria for decision making'[17]. This gives weight to our belief that the assessment criteria should be front and centre in the how your disability affects you form that is sent out to applicants.

# The Problem with PIP

A lack of transparency along with a mammoth form to fill in leaves claimants already ten steps behind. The system must be more honest and claimants must have a fair chance.

## Assessment Stage

We were overwhelmed with the responses to our survey. When we asked the question 'is there anything you'd like to tell us about the assessment', the replies were damning. Claimants told us that the assessments made their health worse, using words like 'dehumanising', 'traumatic' and 'terrifying' in their responses. This should ring alarm bells. For anyone who is already living with a life-changing condition, the last thing you want is to be made to feel this way. We could write a whole report on the inhumanity of the assessments, but there are a few key things that could be changed that would make a real difference.

We believe that face to face assessments should only be used when absolutely necessary. If you have reported mobility issues in your application and are then being asked to travel, you are being asked to do what you have explicitly stated you cannot do. One of our survey respondents told us about the lengthy journey he and his wife (the claimant) had to make to the assessment centre:

*'My wife has spinal stenosis, we arrived 10 minutes early and went in 2 hours late. It's a 100-mile round trip to the assessment centre and there were no comfy seats available for people with spinal problems. My wife spent the next 10 days in bed recovering from the ordeal.'*[18]

This claimant was not awarded PIP after the assessment but went on to be successful after submitting a mandatory reconsideration. A clear failure of the assessment stage.

# The Problem with PIP

Face-to-face assessments are equally difficult for those with severe mental health issues. For many who suffer from mental ill-health, the act of getting out of bed and leaving the house is often impossible. This is not to say that assessments done over the telephone or via video call are any less traumatising for claimants, as one of our respondents who lives with mental ill-health as well as ADHD told us:



Single most humiliating experience of my life. **I felt less than inhuman.** I felt like the experience actually made me more unwell.



There are also issues with the fact that assessors seem to place a heavy emphasis on appearance. The charity Mind carried out an investigation into the PIP process and reported:

*'Many of these informal observations do not provide insight into someone's mental health or how it affects them. The fact that assessors had not explicitly discussed these observations before recording them also meant that they had not taken the time to consider whether they provided a representative picture of how that person usually is'*

*-Mind [19]*

# The Problem with PIP

We have seen the same issue with our own clients. It is hard to assess someone based on appearance alone. We have had clients told they did not appear anxious, for example. It cannot be right to judge the level of support someone needs based on their looks or judge their mental health based on one conversation.

As part of our research, we looked at a sample of decision letters that had been received by our clients over the past few years. Analysing the language used by the DWP, we broke the letters down into common phrases and labelled these by inference. The reasons given in decision letters for denying PIP for our clients boiled down to three themes:

- 'Specialist input'
  - The applicant was not eligible for PIP as they were not receiving support for their condition by someone more specialist than their GP. The inference here is that, if you are not receiving help for your condition above a GP level, you are not sick enough.
- 'Medication'
  - The applicant was not eligible for PIP as they were not on the required level of medication for their condition to be perceived as serious enough. This was particularly the case for those with mental health conditions. Many clients were left feeling that as they were not prescribed medication at a high dosage, their condition was invalid.
- 'Diagnoses'
  - The applicant was not eligible for PIP as their symptoms had yet to result in an official diagnosis. This can feel invalidating as it can take months or sometimes years to reach an official diagnosis, particularly for invisible conditions.

# The Problem with PIP

A sample of phrases taken directly from decision letters can be seen here:

	Examples	
Specialist input	'You are not receiving a high level of input for your eating disorder. You are not receiving any dietician input'	'Your history of conditions shows no psychiatrist input for mental health conditions'
Medication	'You are prescribed a low dose of mental health medication'	'Currently there are no prescribed specific medications to treat anxiety'
Diagnoses	'You do not have a diagnosed eating disorder'	'There is no evidence of an official diagnosis'

It is wrong that someone's daily needs are invalidated if they do not have the 'correct' level of treatment, medication or a diagnosis. We are consistently told that PIP is based on how your condition affects you, not diagnoses. Medication is not a good enough indicator of someone's health:

*The NICE guidelines for treating depression recommend that doctors offer you a type of talking therapy or counselling... Therapy may be offered instead of antidepressants, or in addition to them.*

– Mind[20]

Of the decision letters we receive, the vast majority go on to have the decision overturned at the Tribunal stage. If there were widely available transcript or recordings of the assessments. It would cut out hours of administration needed to prove the decision letters are an inaccurate recording

# Client Story B



I felt ashamed and untrusted.

I found a lot of questions irrelevant to my personal circumstances and struggles. Felt little compassion which **made me feel ashamed and judged.**

Assessment results showed little understanding and I had to go through an appeal , which I found extremely traumatic.

I find it hard explaining how past trauma still affects me and felt belittled by the experience .

I had been mis-diagnosed for years. So I didn't fully understand why I was struggling so much. I found it hard to articulate and express myself.





# Conclusion

Ten years on after the first PIP claim, can we really say that the system has been successful? Our research shows the stark reality. We saw people who had been broken by a system that was meant to build them up. Our survey of PIP claimants resulted in some shocking, but not altogether surprising results. We pulled out the most common words used to describe the process:



This is completely unacceptable. For a system that was set up to make the benefit system fairer, more affordable and reduce poverty, the result has proven to be the entire opposite. The system is unfair, unaffordable and leaves people spiralling further into poverty. People who have health conditions are already struggling, to put them through a stressful and traumatic process to access the help they are eligible for is inhumane.

Appeal systems are not designed to overturn three quarters of an organisation's decisions, rather to act as a safety net to catch the minority of incorrectly handled cases. The huge levels of erroneous decisions clearly indicate that the process is not fit for purpose and reform is long overdue. Personal Independence Payments represent ten years of hardship, ten years of money wasted and a ten year mistake.

# Recommendations

As a result of our research, our recommendations to the Department for Work and Pensions can be summarised in the following infographic:

The infographic is a purple rectangular box with a white title 'Recommendations' at the top. Below the title are five numbered items, each consisting of a white square with a number and a white rounded rectangle with text. The items are:

- 01 The points system should be printed on the front page of the "How Does Your Condition Affect You" application form
- 02 Health care specialists who conduct assessments should be experts in the claimant's disabilities/conditions
- 03 Recordings or transcripts should be taken of assessments
- 04 More emphasis should be put on medical evidence rather than the assessment report
- 05 Face to Face Assessments as a last resort when the decision genuinely cannot be made based on the papers

We believe these changes would make the system work in the way it was intended to. A more open, accountable process that does not discriminate against those it is meant to help.

We urge the Government to look again at the PIP project, and implement our recommendations for the sake of the most vulnerable in society. In the run up to a General Election. It is time for a rethink. Time for change.

# Client Story C



The process isn't fit for purpose.

The DWP don't follow their own rules regarding which descriptor a claimant meets for an activity.

Clear evidence proving the facts, such as letters from consultants is disregarded.

Instead more weight is placed on the reports written by medical professionals **who have very little or no knowledge of the conditions they're assessing.**



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# Glossary

**ATOS** - private company used by the DWP for benefits assessments

**Capita** - private company used by the DWP for benefits assessments

**DLA** – disability living allowance

**DWP** – Department for Work and Pensions

**HMCTS** – His Majesty’s Courts and Tribunal service

**HMRC** – His Majesty’s Revenue and Customs

**Mandatory reconsideration**

**Means-tested** – benefits that are given dependent on income

**Needs-based** – benefits that are given dependent on need not income

**PIP** – personal independence payments

**Recourse to public funds** – immigration status that allows you to access benefits such as universal credit

**Sanctions** - punishments given to claimants by the DWP in the form of withdrawal of support

**SDP** – severe disability premium

**Tribunal** - a hearing to discuss the appellants reasons for appeal

**Upper tribunal** - the higher level of tribunal that hears appeals against decisions made by the first tier tribunal based on legal technicalities



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