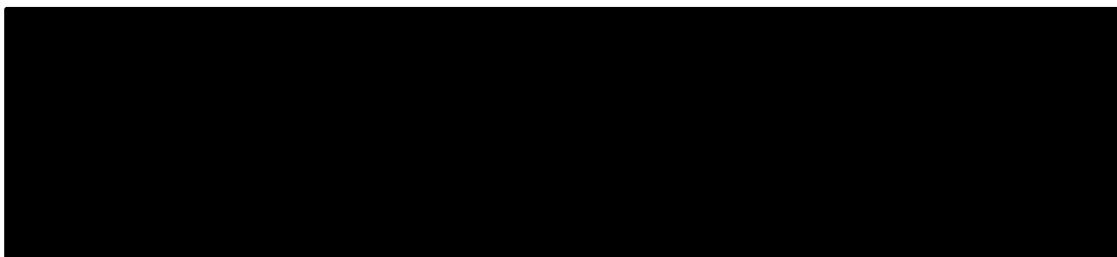


# BLACKBURN AND DISTRICT TRADES UNION COUNCIL



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Response to "Modernising support for independent living: the health and disability green paper"

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Blackburn and District Trades Union Council is a local Trade Union body, registered with the Trades Union Congress, comprising delegates from Trade Unions with members working or living in the Boroughs of Blackburn with Darwen and the Ribble Valley.

We write to respond to this Green paper, which seeks views on the possibility of reforms to the Personal Independence Payment (PIP).

The first point we wish to make is that it seems to us to be inappropriate for the Government to be diverting resources to a review of PIP at a time when the immediate priority ought to be improving on the delivery of the benefit as it currently stands.

The National Audit Office Report "**Transforming health assessments for disability benefits**" (22.06.23) found that *"Between April 2018 and March 2022, 12% of initial claim decisions (15% of DWP's initial PIP claim decisions, where the claimant was not initially awarded the maximum daily living and mobility components of the benefit), were subsequently changed through either a mandatory reconsideration (where DWP reviews the claim) or an appeal to the Tribunal"* and *"only 55% of ESA claimants and 53% of PIP claimants agreed with the statement "DWP cares about the people who use its services"."*

In March this year "**MIND**" conducted a survey that led them to conclude *"The UK government's system of benefit assessments is causing the majority of those with mental health problems who have experienced it to become more unwell"*. In April the "**MS Society**" commented: *"The PIP assessment is riddled with issues,*

*from the 20 metre rule to 'informal observations'. Too many people with MS end up without the support they need".*

DWP may have managed recently to speed up initial processing times, but other problems have then popped up to take their place.

On 4th May 2023 "**Disability News Service**" reported *"Disabled people trying to contact the Department for Work and Pensions (DWP) to pass on urgent information about their disability benefit claims are facing delays of more than an hour before their calls are answered. Even when the calls are answered, they are often abruptly cut off before they can pass on the information"*.

"**Benefits and Work**" reported on 13th June that *"Almost half a million callers to the PIP helpline in the month of April were deliberately disconnected by the DWP before they could even wait in a queue, a freedom of information request ..... has revealed. The proportion of calls cut-off before entering the queue is now greater than the proportion who even get to wait for an hour or more before giving up or getting disconnected"*.

According to "**Birmingham Live**" on 23.02.24 *"the average time taken for a decision on a review is now 44 weeks, or about 10 months, and the latest figures from December 31, 2023, showed there was a long list of 440,000 people still waiting for their results"*.

It is particularly galling to us that amid these problems DWP should have decided to close an office in the centre of Blackburn - Cardwell Place - that was dedicated to PIP administration. We do not know if the closure of Cardwell Place affected the overall resource devoted by DWP to PIP administration, but it is "prime facie" frustrating to see that the Government would apparently prefer to have an office standing empty in the middle of our town when it could have continued to have been used for the administration of PIP, possibly to the benefit of avoiding at least some of the inadequacies associated with the benefit

Now (22.05.24) we hear that the **Equality and Human Rights Commission** is opening an enquiry as to *"whether the Secretary of State for Work and Pensions, or his employees or agents, have broken equality law"* in failing to anticipate and make reasonable adjustments for disabled people with a mental impairment during health assessment determinations for PIP and ESA.

The expression "fiddling whilst Rome burns" comes to mind.

It is also a matter for concern that the very first sentence of the Executive Summary of the Green paper - *"we are determined to have a welfare system that provides a vital safety net for those who need it most, whilst encouraging and supporting people into work"* - implies a context of PIP and employment being alternatives. It should be remembered that the basic idea of PIP is to help people with additional costs that may arise from a disability whether or not they are in work.

We think it is important to keep that in mind. PIP is not a key element in the dialogue between disability and work. We see these as being: support for people when they are out of work because of a disability or ill-health, which is the job of ESA; the extent to which employers offer reasonable adjustments (and whether they can be supported in so doing); "Access to Work" type schemes; and discouraging employers from dismissing staff on grounds of ill-health.

It is reasonable to ask how far the distinction made actually holds water in the real world, when organisations like SCOPE have suggested that some people really use their PIP payments simply to help them cope with basic daily living costs - but we think it is the case that having a disability can present a person with additional expenses, and that the principle behind PIP should not be threatened because of the insufficiency of means-tested benefits and low wages.

It is a further matter for concern, in respect of the Green Paper, that the Secretary of State should early on introduce the question of financial sustainability, by saying: *"I am concerned about the sustainability of the current model. Over the coming 5 years, PIP spending is expected to grow by 63% (£21.6bn to £35.3bn, 23/24 to 28/29). There are now over 33,000 new awards for PIP per month compared to 17,000 before the pandemic"*. We should be looking at what is required, and then deciding if it is "affordable". The two issues should not become entangled, as mixing them up can skew the process towards the tendentious.

The same applies to focus on the increase in "mental health" claims: *"many more people being awarded PIP now have mental health conditions than when it was first introduced"*. How is that relevant to the stated purpose of the Green Paper? The issues put forward for consideration should be assessed irrespective of the number of claims or of their clinical background.

The Prime Minister said on 19th April that: *"We also need to look specifically at the way Personal Independence Payments support those with mental health conditions. Since 2019, the number of people claiming PIP citing anxiety or depression as their main condition, has doubled... ..with over 5,000 new awards on average every single month. But for all the challenges they face.....it is not clear they have the same degree of increased living costs as those with physical conditions"*. But the Green paper completely fails to look at this issue "specifically". As things stand, it seems to lurk in the background as an ulterior motive. It suggests that behind questions such as *"Do you think any of the PIP activities should be removed or re-written and why?"* there is already a plan to re-draft then in such a way as to make people with mental health issues less likely to be eligible. This is, frankly, an underhand way of going about things.

## **Chapter 1 - assessment**

The Green Paper seeks to disentangle views on assessment from feedback previously received on the process. This is hardly credible, since the delays, dissatisfactions and levels of successful appeal associated with the current process must surely influence, at least to a degree, any judgement as to whether it is well-designed.

It seems to us that the fundamental problem with a "condition-based" process is that there are conditions - from arthritis to anxiety - whose impact on individuals varies enormously. On the other hand, a process that completely rules out reference to conditions risks an overload of otiose assessments.

**"Benefits and Work"** published figures from February 2023 showing the proportion of claims allowed by condition - Success rates for PIP claims by condition ([benefitsandwork.co.uk](http://benefitsandwork.co.uk)) - showing that very few are over 90%; so there would need to be, it seems, quite a bit of reflection on what conditions could be made, effectively, 100%.

Simultaneously, one of the key dissatisfactions with the existing PIP process is a lack of confidence in the "Health Professional" idea. The majority of "Health Professionals" carrying out PIP medicals are physiotherapists with very little knowledge of mental health issues, learning difficulties or more complex physical conditions. There are also some occupational therapists, nurses and, very occasionally, doctors. They only receive around a week's training and much of this is about how to use the computer software and how the points system

works. A common complaint is that they just don't have the necessary breadth of understanding and experience.

It would no doubt be of help to both claimants and administration of the system if a proportion of decisions could be made on the basis of specific health conditions or disabilities as evidenced by claimants' own NHS clinicians. But this does not mean that provision of evidence or a formal diagnosis should be mandatory, and there would still be a need for an assessment process in a proportion of cases. Assessments should allow for "once and for all" decisions.

## **Chapters 2 - range of descriptors alternatives to cash**

Whilst it is true that there is no monitoring of what recipients actually spend their PIP payments on, an issue with PIP is precisely that, as a hangover from DLA, entitlement still depends on claimants demonstrating need in specific areas. It is intended to assist where the individual has *"difficulty doing certain everyday tasks or getting around"*, and so it is arguable that there are extra living costs that may be associated with having a disability that it does not consider.

The way PIP works is that it guesses that a given level of capacity across care need and mobility descriptors can be presented as a level of assessment to which can be attached a monetary value.

### The Green Paper

A) poses the possibility that consideration of fewer descriptors could lead to just as accurate an assessment for these purposes, and

B) poses the possibility that help with the costs of disability could be provided in the form of specifics, rather than as an overall payment.

It consequently misses the most obvious question to ask first, which is whether a process focussing on "care" and "mobility" captures *all* the additional costs that come with having a disability, though Para. 79 does go some way towards recognising that these exist.

It is perhaps understandable that the Green Paper has not been able to consider the findings of the House of **Commons Work and Pensions Committee** Report *"Benefit levels in the UK"*, since it was only published in March of this year, but it is surely relevant to the discussion that it found (para 48):

*"When considering PIP itself, we heard that many claimants experienced a significant shortfall between the levels of support provided and the cost of additional health and disability related costs. Scope's Disability Price Tag 2023: the extra cost of disability report found that households which included at least one disabled adult or child faced additional costs on average of £975 per month, even after accounting for PIP (or £1,122 per month when updating the figure to reflect inflation over 2022–23)<sup>102</sup>. Macmillan Cancer Support estimated that 83% of people with cancer experience a financial impact from their diagnosis, averaging an additional £891 a month. For the 39% most severely affected by cancer, they were estimated to be on average £1,038 worse off a month following their diagnosis".*

In Para 93 they commented *"the New Economics Foundation used MIS (Minimum Income Standard) as a comparable baseline to assess benefit levels in their written evidence and estimated that in 2021 PIP "covered only 36% of the additional income a disabled person required to afford a decent standard of living".*

In November 2023 **Daniel Jennings, Epilepsy Action's senior policy and campaigns manager**, said: *"Last autumn, almost 3 in 5 people with epilepsy were worried about being able to afford their bills, including the cost of running equipment such as vital seizure alarms and monitors, and 2 in 5 were experiencing more seizures due to stress about managing rising costs".*

Clearly, the second big challenge facing PIP, after getting its administration up to scratch, is ensuring that the payments it makes come closer to meeting the actual additional costs of disability that people face.

In respect of how assessments are conducted and what they should take into account, we think it would generally be welcomed if they were to be made simpler, more wholistic and more dignified. Surprisingly (really?) the Green Paper does not seem to want to refer to the project in Scotland, of replacing PIP with the "Adult Disability Payment" (ADP).

ADP has "carried over" many aspects of PIP, but it at least tried to address some of the issues associated with PIP assessments. **Stephanie Millar, Citizens Advice Scotland policy manager (Social Justice Team)** wrote in March 2022:

*"ADP has been designed to be a person-centred process, limiting what the claimant needs to source and provide. So a key difference is that people no longer need to tie themselves in knots collecting, and often paying for, additional medical information to support their claim. This removes a huge burden from the claimant, as Social Security Scotland will take the information provided and collect the additional information itself. And as all evidence will be treated equally, information from family or carers is given the same weight as that of a medical professional.*

*"The second major difference is that medical assessments will be used as a last resort and only if a decision can't be made on the evidence gathered. And they will be carried out by people with knowledge and experience of the claimant's specific health conditions".*

The comment in the Green Paper that *"Our aim would be to ensure that the criteria are fair and that we focus support on people with the highest needs and significant ongoing extra costs"* suggests, however, that what the Government is really thinking it wants is a "tightening", rather than a less stressful, process. In their 2023 Report **"Ten Years of PIP - A Decade-Long Mistake?"** **Reading Welfare Rights** commented *"Our clients tell us every day how humiliating, intrusive and traumatic the process applying for PIP is"*. That is what any review of the criteria should address - not how to make claims even more difficult.

We welcome the Parliamentary Day Motion 678, which states:

*"That this House expresses its concern about the application and assessment process for disability benefits such as Personal Independence Payments and Universal Credit Limited Capability for Work and Work-Related Activity; notes that the Government is proposing to end GP involvement in the process; further notes that disability rights campaigners have argued that phone assessments and to a lesser extent face-to-face assessments do not give an accurate understanding of someone's ability to work or the level of support they need; believes that GPs have a role to play in the assessment of disability needs; and calls on the Government to review disability benefit assessment processes with the aim of creating a system that is easier and friendlier to navigate for people with disabilities."*

### Chapter 3 - alternatives to cash

The most fundamental objection to the proposal that PIP should offer alternatives to "cash transfer" was actually given by the Secretary of State to the House of Commons Work and Pensions Committee: see Para 59 of "**Benefit Levels in the UK**" - *"In evidence to us, the Secretary of State acknowledged that the extent that health and disability related costs were covered would vary between claimants. He added that it would be an "immensely complicated bureaucratic process if one were to look at every single individual, work out exactly what they need and calibrate the exact amount to cover it"."*

At the most basic level of plausibility, replacing a cash benefit with a plethora of alternatives would create additional administrative complexities for a system that, as we have pointed out, is already creaking at the seams.

The process envisaged risks mixing up what PIP provides and the sort of functional assistance one would expect the health and social care systems to deliver (as does Chapter 4). This is most clear in the raising of questions such as *"Instead of cash payment, are there some people who would benefit more from improved access to support or treatment (for example, respite care, mental health provision or physiotherapy)?"*.

Of equal concern is that the proposed measure is perceived as exhibiting a lack of trust in people with disabilities and will become yet another way in which they are demeaned and stigmatised. The **Disability Poverty Campaign Group**, for instance, says *"Being offered vouchers in any proposed reform insults PIP recipients who are rigorously assessed, and reassessed, to determine their entitlement to PIP. We will use all possible avenues to challenge the implication that Disabled people eligible for PIP lack the capacity to manage cash-based income"*.

The proposal risks making even worse the culture that the **UN Committee on the Rights of Persons with Disabilities** has described as *"...a pervasive framework and rhetoric that devalues disabled people and undermines their human dignity. Reforms within social welfare benefits are premised on a notion that disabled people are undeserving and wilfully avoiding employment ("skiving off") and defrauding the system"*.

PIP does offer a degree of relief to the situation in which people with disabilities tend to find themselves disproportionately affected by low income and poverty.



The **UN Committee on the Rights of Persons with Disabilities** March 24 *"Report on follow-up to the inquiry concerning the United Kingdom of Great Britain and Northern Ireland"*, for instance, noted: *"Several sources informed the Committee that disabled people are among the groups most severely affected by these economic challenges as they are already more likely to live in poverty, with a disposable income that is approximately 44% lower than that of other working-age adults, exposing them perilously to the rising cost of essentials. A notable 41% reported they could not afford to keep their homes warm in winter 2022, and one in ten have fallen into debt due to the crisis"*. It also pointed out that *"deep poverty is more common among disabled people, particularly those living alone, who cannot share costs and are twice as likely to live in deep poverty compared to single persons without disabilities. Additionally, disabled people constitute most food bank users in the UK, with recent research indicating that 69% of working-age people using food banks are disabled people, highlighting a stark contrast to the 23% prevalence in the general population"*. The additional financial support of PIP gives a level of flexibility in response to these challenges that provision "in kind" will not.

**Greater Manchester Poverty Action** have given a range of reasons why a "cash-first" approach is generally preferable in meeting living cost challenges:

∅ Giving people dignity by removing the stigma that often comes with using in-kind support.

∅ Giving people choice and control by enabling them to use support in a way that works best for them, enabling them to meet the multiple needs that they have. This boosts household wellbeing and has significant benefits in households with dependent children.

∅ Giving people what they want – cash is the preferred option for most people on low incomes.

∅ Simplicity and efficiency - Cash payments are the most simple, efficient and cost-effective means of providing people with support as cash payments can be made directly into people's bank accounts. It can be a more efficient approach for local authorities as it removes need for the partnership arrangements that come with in-kind support.

∅ Increasing take up - Cash payments encourage greater take up of support by households experiencing financial hardship.

∅ Giving a boost to the local economy by increasing the likelihood of payments being spent with local, independent retailers.

Ø Preventing people from falling into high interest debt when they face a financial crisis, and therefore preventing them from spiralling deeper into hardship.

The context in which the Green Paper was published gives cause for concern that the driving motivation is a belief that some people are "out of work" as a temperamental choice and that there is a need to control spiralling costs. The Prime Minister set the context for it as follows: *"We now spend £69bn on benefits for people of working age with a disability or health condition. That's more than our entire schools budget; more than our transport budget; more than our policing. And spending on Personal Independence Payments alone is forecast to increase by more than 50 per cent over the next four years. Let me just repeat that: if we do not change, it will increase by more than 50% in just four years"*.

No wonder that **"The Big Issue"** could report on 24th April that ***"Helen Barnard, director of policy at the Trussell Trust, said: "Today's suggestions on overhauling social security support for disabled people from the UK government look more like cost-cutting rhetorical flourishes than serious policy proposals"***.

#### **Chapter 4 - aligning support**

This section is so brief and under-developed that it is difficult to understand what it means. We feel that there is often a degree of obscurity as to where the dividing line falls between "health" and "social care", but the services of both are about, in a sense, addressing fundamental functional needs - equipment like a walking frame or personal alarm, home improvements such as a walk-in shower, practical help from a paid carer. Individuals who have a 'needs assessment' via the LA social care will be entitled to the equipment mentioned above free of charge regardless of "means" or benefit entitlements. PIP presumes that, on the whole, people will not have to pay for these sorts of things but that there are, nonetheless, extra costs to being disabled that a functional assessment cannot address.

Overall, there is nothing we can identify in the "Green Paper" that we feel will be of benefit to people with disabilities, and much that might prove to their disadvantage. The placing of its proposals in a context where sickness is seen as being a problem for the nation rather than for the people affected, and where there is even a suggestion that illness might be "disincentivised" are instructive in revealing the extent to which the Governing class are divorced from the realities experienced by people with disability, whose advocates put the matter

far better than we can. The Government should be working in dialogue with organisations representing people with disabilities. If that were the case, we believe that this Green Paper would not even have seen the light of day.

Ian Gallagher  
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