

# **“Punished for going to work”**

**The experience of UNISON  
disabled members claiming  
Personal Independence  
Payments (PIP)**



## 1. EXECUTIVE SUMMARY

1.1 UNISON undertook a survey of disabled members experience of applying for Personal Independence Payments (PIP) in 2018.

1.2 Key findings from the survey were as follows:

- 93% of respondents were in employment.
- 64% of respondents were not happy with the outcome of their PIP assessment
- 70% said it affected the amount of money they received or what they could get, for example a mobility vehicle
- Only 26% said the change from DLA to PIP and how this might affect the amount of money they received was explained to them.
- 56% of respondents did not think the PIP assessment took account of things they thought were relevant
- 18% of decisions were later overturned on mandatory reconsideration or appeal
- Members reported the following issues:
  - the quality of the assessments in terms of qualifications, training and understanding of assessor
  - non-apparent and fluctuating disabilities, including mental health, not taken into account
  - penalising claimants for being in work
  - treating claimants as dishonest
  - timeliness and location of assessments

1.3 Recommendations include:

- Better quality assessments
- Rethinking work and disability
- Stop treating disabled people as ‘benefit cheats’
- Ending privatisation
- Support for the appeal process

Overall the social model of disability needs to be fully embraced so that dignity and respect for disabled people’s independence is at the heart of the PIP process.

## 2. ABOUT UNISON

2.1 Unison is the UK’s largest trade union with 1.4 million members. Our members are people working in the public services and for private contractors providing public services including in the essential utilities. They include frontline staff and managers working full or part time in local authorities, the NHS, the police service, colleges and schools, the electricity, gas and water industries, transport, non-departmental public bodies and the voluntary sector.

2.2 UNISON is committed to self organisation and has a strong self organised disabled members group which operates on a branch, regional and national level. Members and activists have increasingly raised the issue of the Personal Independence Payment system and the impact this is having on our members. This prompted UNISON to carry out a survey of disabled members who had applied for PIP.

### 3. METHODOLOGY

3.1 The PIP survey was distributed via a targeted eBulletin to UNISON members who identify as disabled in March 2018. Respondents were asked a number of questions relating to their PIP claim. Only UNISON members were surveyed.

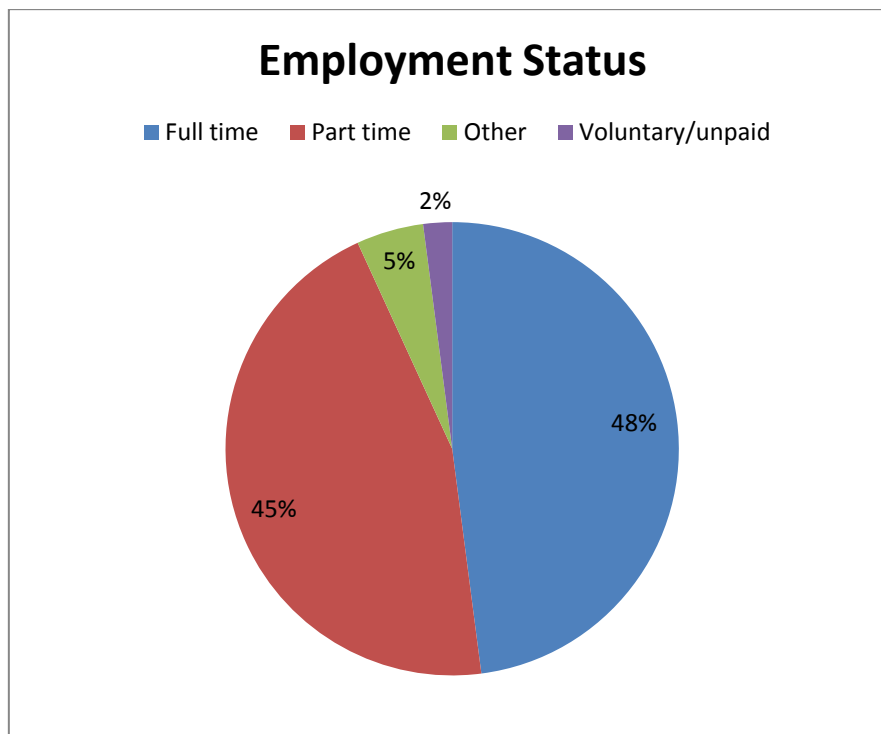
### 4. SURVEY RESULTS

#### The respondents

4.1 163 disabled members of UNISON responded to the survey.

4.2 93% of respondents said they were in full or part time employment.

4.3 48% were in full time employment and 45% in part time employment. 7% were student, retired or unemployed members of UNISON.



4.4 A small number of those who said they were not currently in employment were currently off sick or had retired or been laid off due to ill health.

## The Assessment

- 4.5 There were some examples of good practice with 88% of respondents given the chance to be accompanied by a family member to the assessment. 66% of these chose to be accompanied.
- 4.6 However only 24% of respondents were given the option of having their assessment at home. 62% of these chose to avail of this offer.
- 4.7 Respondents were asked who undertook their assessment. They were split fairly evenly between having their assessments conducted by Capita (30%) and ATOS (33%), with the rest unsure.
- 4.8 54% said the change from DLA to PIP and how this might affect the amount of money they would receive was not explained to them and 20% weren't sure. Just 26% of respondents said that this was explained to them.
- 4.9 There were significant concerns reported about how the assessments were undertaken. 56% said that they did not think the assessment took account of things they felt were relevant. However 44% of respondents felt that the assessment did take account of things they felt were relevant. This suggests that there may be inconsistencies in the assessments that are leading to differential outcomes.
- 4.10 A small number of people who felt the assessments took account of what was relevant commented further. One said they were given plenty of time to respond and allowed to add more at a later stage. Another said their assessor was an ex-nurse which helped her to understand the symptoms being described. A third respondent said they were lucky because the assessor understood their condition and guided them.
- 4.11 However the remaining 73 of 76 open text responses to this question all reported negative experiences. A number of respondents said that the assessor wasn't listening and was just asking questions from their screen. The assessors were reported as using closed questions and shutting down further responses.
- 4.12 A significant number said that the assessors focused on physical impairments with mental health not taken into account. Respondents with mental health problems found they were assessed for their physical mobility when this was not a barrier they faced whilst the impact of their mental health problems was not assessed.
- 4.13 Others reiterated that the assessment focused on mobility, with the impact of pain and of fluctuating conditions also ignored. The impact of fatigue and pain on the ability to stand or walk was not assessed. As one member stated, "they were assessing the wrong kind of disability".
- 4.14 Some said medical evidence including consultants' reports were ignored.

## The Outcome

- 4.15 64% of respondents were unhappy with the outcome of their assessment.
- 4.16 71% stated their PIP assessment affected the amount of money they received.
- 4.17 Respondents were asked how much money they lost when switching from DLA to PIP. Some of the members responding were making their first claim so they had not experienced a change.
- 4.18 However others reported significant losses with one member saying they had lost £7,000 a year. Several others said they had lost over £400 a month.
- 4.19 In some cases the PIP assessment also resulted in the loss of tax credits and local council tax support. One member said they had lost over £400 a month and could no longer afford their medication, another said they had lost £310 a month they got from DLA, another £200 a month from reduced council tax and that their carer had lost £120 a week from carers allowance and income support.
- 4.20 Many more reported losses of between £60 a month and £320 a month.
- 4.21 Some members reported their losses by describing the change to their assessment without putting a cash figure against it. Examples include:

***“Higher to standard rate mobility”***

***“Care component halved mobility lost completely - impact on tax credit - bus pass lost”***

***“Higher DLA to zero”***

***“Higher rate mobility component and lower rate care component”***

- 4.22 For others the loss of their car had the most impact.

***“Lost money but biggest loss vehicle”***

***“My car”***

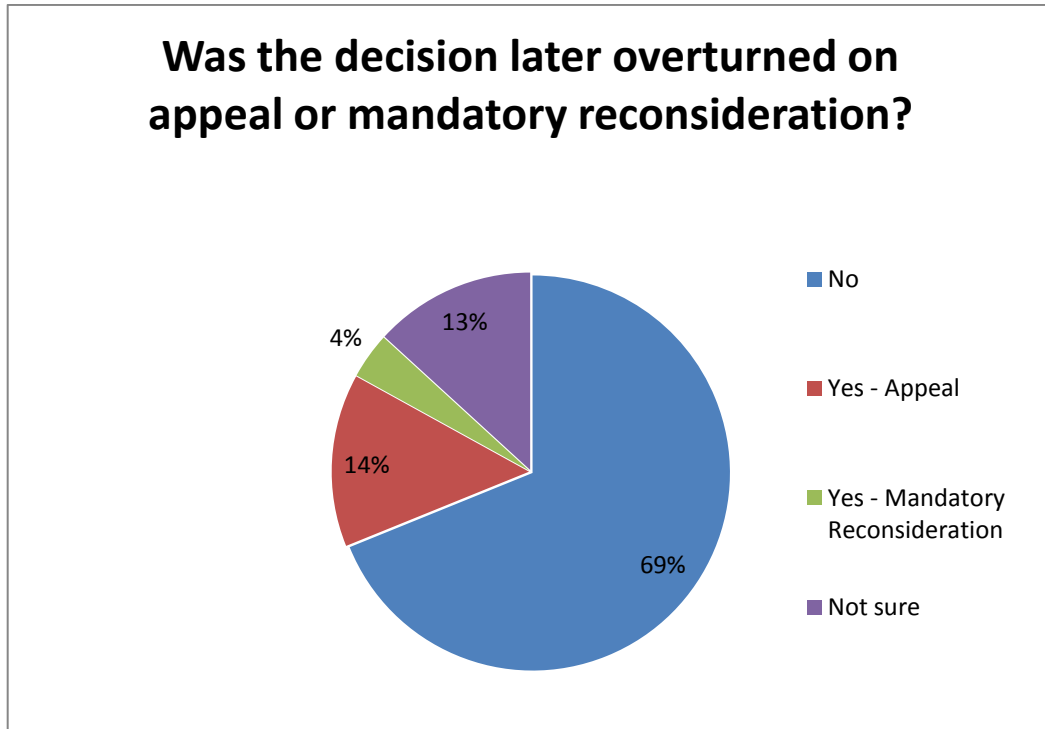
- 4.23 Several recounted their struggle making an appeal against wrong decisions. For example:

***“Reduction meant not enough points for a car. Motorability took car back immediately - then I had to appeal - CAB helped me - we won after 6 months delay .Took ages to get car sorted. Plus wasn't told could spend PIP mobility to buy car and not lease. When awarded - friend told me so I bought one.”***

***“Initial refusal cost 12 months money”***

***“no money for 6 months - recovered on appeal”***

4.24 18% of respondents had their decision overturned on appeal or mandatory reconsideration.



4.25 Just 4% of claims were overturned at mandatory reconsideration compared to 14% at appeal. The lower mandatory reconsideration figure may well be a result of the reported attitude from assessors and decision makers to disabled people in employment.

4.26 13% weren't sure which suggests they may still be awaiting a decision.

4.27 36% did not appeal. One member said they were "too scared" to ask for mandatory reconsideration in case they lost the lower rate they had been awarded. Another member stated that they didn't appeal as their previous appeal had been so traumatic.

## **5. KEY CONCERNS**

***“If you have mental health issues, you're screwed, if you do not have a lot of experience with the system, you're screwed. If you are not able to read up on extensive advice that is outthere (Citizens' Advice etc) and not able to express yourself properly you're screwed.”***

5.1 There were very obvious patterns in the experiences our members recounted of applying for PIP. Some clear concerns emerged as themes.

5.2 Quality of assessments

***“I feel qualified medical professionals should undertake assessments and make decisions. The assessment should not be tick box and scored as this does not represent a person’s needs. The assessment is based on a one size fits all and it isn’t right. It should be a discussion with the medical professional who will make an informed decision.”***

5.3 Many members stated that assessors need to be better trained and should have relevant qualifications and experience.

***“No disrespect to paramedics but they are NOT doctors or consultants”***

***“I felt the interviewer was listening, but not really taking things 'on board' - sort of dismissing them as unimportant. They were just 'going through the motions'.”***

***“Physiotherapist to interview Mental Health Patient”***

***“How can a mental health nurse assess someone with a neurological illness. I look well and present well and don’t look ill.”***

***“I wasn’t asked questions relating to my MS. I felt that I was deceived as I later found out that the assessor was a Physiotherapist not qualified as an MS specialist.”***

***“The paramedic who took the assessment clearly has no knowledge of lymphoedema and how it affects a person, because of this I lost the mobility part of pip my funds were reduced and my struggle still goes on. He more or less inferred I am cured of a disability there is NO CURE for, that I have the capability to walk normal distances because he watched me walk from the chair to his office.”***

5.4 Members stated that the assessors did not listen, did not take medical reports into account and used a one size fits all assessment process.

***“Ignored the GP’s report and my records”***

***“Had her head in the computer most of the time and didn't listen to my replies properly”***

***“Interviewer had not read my notes and was only asking questions from her screen.”***

***“The nurse assessor did not even make eye contact and I felt she did not take into account my medical evidence”***

***“I had taken in recent medical evidence and the agent said they had enough from my GP, whilst I had brought in a letter from my consultant”***

***“Didn’t appear interested in what my daily routine involves, only what was on the screen in front of him.”***

***“Assessment itself was too generic, a one-size-fits-all tick box exercise grossly simplifying multiple, interacting illnesses and symptoms with complete disregard for cumulative effects.”***

***“Rigid questions about general disability and not individuals”***

***“They didn’t listen at all”***

***“I don’t think it really considered everything. I felt as though I was having to fit into a box”***

5.5 A lack of empathy and compassion was raised by a number of respondents.

***“The assessor did not let me explain. Used closed questions and cut me off.”***

***“I wasn’t given time to explain myself I was cut off during every answer.”***

***“The assessors give the impression of lacking any human understanding during the process.”***

5.6 Some people said their assessment unfairly included time when they were waiting or accessing the premises.

***“How I parked and entered the building prior to assessment, plus how I behaved in the waiting room was included in report. This info from the receptionist!”***

***“Later I was told that they had watched me walk to my car, and from that decided my mobility was not too bad and not worthy of PIP.”***

5.7 A worrying number of responses questioned the honesty of assessments.

***“They twist things to try and stop you getting what you need”***

***“They were deliberately trying to get you to say that you could do stuff”***

***“They didn’t even listen, put the opposite of what I said in the written copy of report”***

***“They were horrible, tried to trick me, didn’t listen, wasn’t aimed at my condition, didn’t understand, and didn’t put what I said down.”***



***“They made no eye contact and asked if wanted to stop a few times due to anxiety & upset but on the form said I maintained eye contact and didn’t look anxious at all!”***

***“Predetermined outcome was obvious, no matter what evidence was put in front of 'assessor.' Relieved to have taken a witness and recorded the 'assessment' because my witness, the recording, Doctor's report and myself appear to have been at a different meeting than the one attended by the 'assessor.' My witness went so far as to say that the 'assessor' was either wholly incompetent or fabricated her 'assessment'.”***

- 5.8 In light of these feelings of dishonesty, some respondents stated that assessments should be recorded as standard practice

***“One big concern is the fact that the bar for audio recordings has been put very high (claimant needs to provide equipment that can produce two identical copies of CD or cassette there and then, no laptop allowed - I bought two cassette recorders). That makes it much harder to appeal later as it is much easier for the assessors to twist your words etc.”***

***“Admissible recording equipment is almost impossible to get the firms to provide.”***

- 5.9 Hidden/non-apparent disabilities and fluctuating conditions

***“It was assessing the wrong kind of disability”***

A key pattern in responses was the failure of the current system to take into account non-apparent disabilities.

***“I feel the ‘walking’ disabled that have hidden disabilities are discriminated against as we have no label, no plaster to see and no obvious signs regarding the disabilities we have”***

- 5.10 A significant number of UNISON members felt the assessment process did not take into account the experience of people with mental health problems.

***“There was no opportunity to tell them about how my mental health problems affect my disabilities”***

***“The assessment was only interested in how I was physically affected! They weren't really concerned about the mental health side of things and said I was fine as I managed to hold down a part-time job.”***

***“They ignored difficulties I have going out on public transport as a result of anxiety and paranoia.”***

***“I was only assessed on my physical ability when I have mental disabilities.”***

***“The assessment was very physical disability weighted and I struggled to get my point across about my mental health difficulties”***

- 5.11 People with hidden disabilities reported that they felt they had been denied PIP due to lack of understanding of their condition by the assessor.

***“Questions/paperwork and interview felt heavily weighted against people with hidden chronic illnesses.”***

***“Lack of understanding of post-exertional malaise in ME, and the harmful consequences of even minor over-exertion, which includes day-to-day activities such as showering, writing an email, washing dishes, etc.”***

***“The assessment only looked at whether I could walk or whether I had a learning disability. I have CFS/ME and Fibromyalgia. [...] None of this was catered for in their clearly delineated to walking/cognitive disability questions.”***

- 5.12 Many respondents reported that fluctuating conditions were also not properly understood by assessors.

***“Took my abilities on my best day as being the norm, didn’t take an overall”***

***“My MS varies from day to day, so felt that when I was seen not representative of how I can be.”***

***“Did not take into account the relapse/remit element of my disability and that I am working at the moment but condition is getting worse so may not be able to work or need to drop working hours”***

***“I was concerned they took my abilities on a good day as the standard, I have medical conditions which can vary extremely, they took my disability as being as the same all the time.”***

***“I can pass tests and my partner always says I’m ‘Good for an hour’. [...] Being convincing, enthusiastic and articulate for an hour or so has the potential to get me into all sorts of scrapes.”***

Some members argued that a diagnosis of a degenerative or incurable condition should be enough for a PIP award and no further assessments should be required.

- 5.13 The assessment’s focus on measuring simple movement and physical mobility was criticised by a number of respondents.

***“It asks movement questions that have no or little relevance in daily living. It is too simplistic.”***

***“I have significant cognitive impairment after a stroke but capita are only focussing on mobility”***

***“They only seem to be concerned about mobility not any other disability you have.”***

***“When I had DLA I got high mobility, [but] because I am not in a wheelchair this has been reduced by PIP yet my condition has got worse since 2003 when I first qualified.”***

***“I have a condition called Lupus and they wanted to know about my mobility and were not concerned about the debilitating fatigue or the unpredictability of Lupus”***

***“The assessment only looked at whether I could walk or whether I had a learning disability”***

- 5.14 Some members felt that the assessment didn't properly take account of the pain associated with some conditions.

***The face to face never asks if you can do things repeatedly and consistently. In daily life it matters, as does the consequences of an action”***

***“They didn't take into account the fact that I can't stand for long because of extreme pain in my foot”***

***“The mobility element of assessment does not take into account pain/discomfort, only how far you can physically get (at all) with your walking aids”***

***“I don't think it was taken into consideration the amount of pain I am in on a daily basis.”***

- 5.15 Treating disabled people as liars

***“It felt like a police interview and was petrifying”***

A number of members said they were made to feel like they were 'scroungers' or liars in applying for PIP.

***“[I was] treated as though I was lying about being disabled”***

***“The DWP default decision is that you are lying and trying to pull the wool over their eyes”***

***“I am lucky to be alive after the illness I had, and after the assessment (which wasn't even 20 minutes) I was made to feel like a fraud!”***

- 5.16 A number of respondents said they felt like criminals with no entitlement to PIP.

***“The application process is so hard and scary and you are made feel like a criminal for needing to apply”***

***“Throughout the entire process I felt like a criminal having to prove my innocence. Need to change attitude and process to reinstate dignity, respect and support!”***

5.17 For some respondents this attitude led to feelings of shame and loss of dignity.

***“I felt ashamed and embarrassed...”***

***“I feel I lost some of my dignity while being assessed. There is no compassion and you are immediately judged.”***

***“It was traumatic, humiliating and left us disgusted by their treatment.”***

5.18 Penalising working people

***“They need to know disabled people can work. They act like if you’re working you shouldn’t claim PIP”***

There was a strong feeling from UNISON members that being in work was a barrier to them receiving PIP or receiving it at the full rate and that this was used against them by assessors.

***“Being given a low rate because I work is not fair”***

***“I felt I was unduly discriminated against due to the fact that I remain in work”***

Members felt that assessors used the fact that they were in work to stop or reduce their PIP payments.

***“I feel that if a person with a disability is working the assessors take this as the main point of consideration and stop the benefits”***

***“The entire points system does not favour people who try to work again or return full time”***

***“I feel that I was penalised because of the fact that I work. It doesn’t seem to matter how much pain you are in, if you can work you can’t be that badly affected!”***

***“I have bi polar and PTSD and because I have returned to work at the moment they have reduced my payments on the care side and the mobility side.”***

This failure of assessors to understand that disabled people can and do work but still require assistance to live independently was consistently raised and there was a palpable feeling of injustice from members responding.

***“I feel it’s very unfair that because I return to work when I’m well that they reduce my money. I work when I’m well and stay at home when I’m ill. I feel I’m being punished for going to work.”***

One member complained about ESA eligibility being linked with PIP eligibility when they are different benefits designed to achieve different outcomes.

***“The absurdity of needing to qualify for PIP – awarded for personal care – in order to qualify for the disability element of working tax credit (or universal credit equivalent). Just because you don’t need help eg washing yourself etc, doesn’t mean your disability doesn’t disadvantage you in finding/maintaining employment. This is especially important since employed disabled people are often in lower paid and/or part time roles.”***

With 90% of respondents currently in full time or part time employment, there was a strong feeling that disabled people should be supported to continue in their jobs rather than being penalised for continuing to work.

***“People with mental and physical difficulties are also valuable members within the workplace and have a lot to offer. They may not be able to work full-time hours due to health issues but this isn’t always through their own choice and [they] should be financially helped through payments like PIP to be able to live their lives as independently as possible.”***

#### 5.19 Logistical issues

A number of respondents complained about the time taken to get through the process, including time taken to make decisions and lengthy appeal timescales.

***“Had to phone on a number of occasions for outcome, beyond timescales proposed.”***

***“My assessment was for osteo-arthritis. Unfortunately whilst waiting for the appointment I suffered a stroke. My assessment appointment was 10 days after having my stroke. They would not take this into account and said I would need to wait 6 months before applying for any changes. I did this 9 months after my stroke and my assessment appointment at home has been cancelled 5 times since January.”***

5.20 For others there were barriers in terms of the accessibility of the premises.

***“Did not take into account what I said, including asking for a room with no perfume or air fresheners and being hit by both at assessment”***

***“I did not feel comfortable and was not given any assistance by them to open the heavy door to get in and out. “***

***“They made me travel a long way to the assessment.”***

***“I was not given notice that it could be a long walk from the reception to the assessment room. I wasn't asked how I felt when I was seated. Had I known how far it would be, I would have taken my wheelchair.”***

***“Until I got it changed to a local office they tried to send me from Leicester to Coventry for an 8:30 am appointment when they were told getting ready in the morning is difficult.”***

***“The venue for the assessment wasn't easily accessible to road vehicles (ie. a drop off, a wait until the driver can park up and then a walk through a pedestrianized area in my case)”***

***“[Was] sent an appointment in Swindon, which I was obliged to attend. I queried this and was told that within 60 miles of my home address was valid, benefit would be stopped if I failed to attend. All disabled parking info provided on assessment confirmation was some distance away from assessment centre. Ringing to query on-site parking took me to call centre with no knowledge of the Swindon site or its direct contact number. I only discovered there was on-site parking when receptionist rang me to confirm my attendance. On arrival outside the building security barrier, I had to ring for her to come out and let me in.”***

***“Felt like I wasn't treated with respect and having to attend an office on an industrial estate made me feel even less happy.”***

## 5.21 Privatisation

***“They need to stop Capita and the other companies doing the assessment. It needs to go back to the government. At least they took everything into account and had empathy and sympathy for people with invisible disabilities”***

A number of respondents commented negatively on the private companies contracted to carry out the assessments. In particular there was a feeling that they were working to targets for turning applicants down and reducing the overall welfare bill.

***“Assessments [should be by people] working for government not private companies told to reduce spending”***

***“PIP should treat people with dignity and consider things in depth and not treat people as targets”***

## 6. IMPACT ON UNISON MEMBERS

6.1 We asked the 90% of respondents who are in full or part time employment what impact their PIP assessment has had on their work or their ability to do their job.

- 6.2 We also asked respondents if their PIP assessment had meant other changes to their life and if so, what these changes were.
- 6.3 The impact on members depended on whether they were happy with the assessment outcome. Those that were awarded PIP had a very positive story to tell about the way in which it helped them whilst those who were not awarded PIP or had their award reduced saw an impact on their health, work and personal lives.
- 6.4 Some of the many comments from respondents who were successful in their claim included:

***“It’s key to me staying at work”***

***“PIP has been a lifesaver which has enabled us to keep our home”***

***“My successful assessment has meant I am able to continue to work part time and live as independent a life as I can”***

6.5 Impact on income

However where PIP had been refused, members reported a significant impact on their incomes.

***“It’s given us as a family less money per month and on a teaching assistant’s wages every penny counts!”***

***“I can barely pay the bills”***

***“I am unable to make any dent in my debt”***

***“We are struggling to make ends meet each month”***

6.6 Transport to work

The mobility element of PIP allows disabled people to lease a vehicle which can help with travel to and from work. PIP can also cover the cost of taxis for people unable to use public transport to get to work. A significant number of members turned down for the mobility element reported that this was an issue for them.

***“If I lose my van I will be unable to keep my job”***

***“If I cannot get a works pool car I have to get the bus. This is putting more pressure on me. I have been asked if I should redeploy or take early retirement on health grounds”***

***“No car, no option to continue with employer. On sick leave at the moment. But want to work”***

Those that were awarded the mobility component highlighted the difference it made:

***“PIP has given me the ability to return to work full time due to having a mobility car”***

***“I struggled to drive my car so receiving the mobility component meant I could get an automatic car, I can work full time as a charity manager”***

***“I got a taxi to work today as it was snowing. I wouldn’t have been able to afford it before but it gave me the choice”***

## 6.7 Reduction in hours

For many respondents, their PIP award meant they were able to maintain employment on a part time basis to better manage their condition.

***“Allows me to work part time instead of fulltime and still survive”***

For those who were refused PIP, reduced hours were not an option.

***“I physically can’t work full time hours but still have a mortgage to pay and daily living costs. I need PIP so that I can still work but at less hours”***

***“I am struggling to maintain my current attendance at work for 3 days per week, but can’t afford to reduce my time any more”***

***“I was considering lowering my hours which is no longer feasible”***

However some members reported that the refusal of PIP meant they were forced to reduce their hours when they did not want to due to the financial impact.

***“I have had to look at reducing my hours which will also impact on me losing my home”***

***“I’m not sure if it is worth working full time!”***

***“Had to reduce my hours from 37 to 30 to enable me to do my job”***

***“Fulltime employment not sure but may be unable to get to and from work”***

***“I am now financially dependent on my parents as I can only work part time”***

## 6.8 Health

A number of respondents reported that the whole application process had had an impact on their health.



***“It was such a stressful process it impeded my capacity to work for some months”***

***“The stress caused by this had a great impact in my health and subsequently I had time off work sick”***

***“I suffered undue stress, anxiety, family strains”***

***“The thought of losing my car and finding money to buy one made me ill, I was off work with stress”***

***“I work full time as a cook, it’s a job I love, now I feel each day is a struggle, my health deteriorates, depression worsens, mobility decreases, I’m afraid of losing my livelihood”***

#### 6.9 Impact on other benefits

PIP is often a “passport” to other benefits.

***“Without PIP I wouldn’t qualify for the disability element of working tax credit, and without this I couldn’t afford to live on my wages alone”***

However, those members who were not awarded PIP or saw it reduced consequently lost their entitlement to tax credits and the blue badge scheme.

***“As a result of losing PIP I have also lost my tax credits”***

***“They declined me PIP and because of this I cannot get further help from the borough like a Blue Badge etc”***

#### 6.10 Impact on Independence

The cumulative impact on all of the above is less independence for disabled workers who can no longer afford transport or personal care.

***“Less money = less time to be able to ‘live’”***

***I feel unclean and depressed as I am unable to look after myself as well as I should be able to and I can’t access/afford help”***

***“I don’t go out, I can’t afford taxis like I could on days I couldn’t drive”***

## 7. RECOMMENDATIONS

***“The assessment could [...] allow for a recovery focus, it is very much based on clinical symptoms and focus on what you can’t do. It could be recovery focused to think about what you can do, what you want to do,***

***what would help and how the PIP would help you to get help personal to you and your needs”***

7.1 Members were asked for their ideas as to how UNISON should campaign on the issue and came up with a wide range of ideas. In addition some of the responses to earlier questions suggested further areas of focus in terms of campaigning for changes in the PIP process.

7.2 Better quality assessments

Many respondents reported a lack of confidence in assessors' understanding of their condition. Staff should be properly trained and qualified to carry out the assessments.

***“Assessments need a human element by qualified clinicians who accept GP and consultants notes”***

The assessment process also needs to be radically overhauled so that it is fair to those with mental health problems and to those with fluctuating conditions that mean people have good days and bad days.

The over-reliance on testing mobility needs to be reduced and an understanding of how pain and fatigue may affect the ability to stand, walk and undertake other day to day activities needs to be integrated into the assessment process.

Basic access issues also need to be addressed. Long journeys to inaccessible buildings, lack of parking and sign language interpreters that do not turn up are all fundamental failings that should not be part of a system that is focused on the needs of disabled people.

7.3 Stop treating disabled people as ‘benefit cheats’

There was a strong feeling from respondents that assessors and decision makers simply did not believe them and were trying to ‘catch them out’. The assessment process needs to be seen to be fair and transparent, not a tick box exercise where assessors already seem to have made up their mind.

***“A fairer assessment where you are not made to feel like a criminal or a fake”***

Better training of assessors in disability awareness and the social model of disability could contribute to this change.

7.4 Rethinking work and disability

***“Working should have no impact on a PIP assessment”***

There was a significant pattern of members feeling they had been turned down for PIP because they work. However PIP was designed to help disabled people to live independently, which includes their right to work. For many respondents in receipt of PIP it allowed them to do just this, to remain in work and maintain their independence. Using work as a reason to deny PIP totally undermines the rationale behind the benefit.

An entire culture change in terms of both assessors and decision makers is required for this to happen. Although not a simple reform to effect, UNISON believes it would result in allowing more disabled people to remain in their jobs, in line with professed government policy.

Worryingly, some members only applied for PIP so that they could get their employer to recognise they were disabled and put reasonable adjustments in place. One member said ***“it meant my employers took my disability a bit more seriously”***. As another member said:

***“[Applying for PIP] was the only way I could get the NHS to see I could do a good job with just one simple free adjustment.”***

This suggests that the culture changes needed at the DWP also need to extend to employers.

#### 7.5 End privatisation

A number of members explicitly blamed privatisation for some of the issues with PIP assessments. UNISON believes that the best way to ensure quality assessments undertaken by trained professionals is to take the process back in house. This would allow more consistency in decision making and better oversight of how policies are implemented in practice.

#### 7.6 Support for the appeal process

A number of members said they needed support to appeal their PIP decision. As a trade union, UNISON is an expert in the workplace. We are not benefit advisers and there are organisations that are better at this than us. However the strong feeling from members suggest that they are not getting this help from advice agencies, which may be due to austerity cuts in the voluntary and community sector. Increased government funding to help disabled people to appeal PIP decisions would allow equal access to justice for all.

#### 7.7 Overall, UNISON believes the PIP system needs to be centred around dignity and respect for disabled people. It is vital that the social model of disability is at the heart of the process, with the focus on breaking down the barriers for disabled people so that they can live and work independently.