



Personal Independence Payment –
Independent Review
A Call for Evidence

NAWRA Response

August 2014

The National Association of Welfare Rights Advisers – NAWRA

1. The National Association of Welfare Rights Advisers (NAWRA) was established in 1992 and represents advisers from local authorities, the voluntary sector, trade unions, solicitors, and other organisations who provide legal advice on social security and tax credits. NAWRA currently has more than 240 member organisations.
2. We strive to challenge, influence and improve welfare rights policy and legislation, as well as identifying and sharing good practice amongst our members.
3. NAWRA holds a number of conferences throughout the year across the UK, attended by members from all sectors of the industry. An integral part of these events are workshops that help to develop and lead good practice.
4. Our members have much experience in providing both front line legal advice on benefits and in providing training and information as well as policy support and development. As such NAWRA is able to bring much knowledge and insight to this consultation exercise.
5. NAWRA is happy to be contacted to provide clarification on anything contained within this document. NAWRA is happy for details and contents of this response to be made public.

Purpose of this response

As required by Section 89 of the Welfare Reform Act 2012 The Department for Work and Pensions (DWP) has commissioned Paul Gray CB to undertake an independent review of how the Personal Independence Payment (PIP) assessment is working.

This response is therefore in response to the call for evidence with regard to the PIP assessment process.

Methodology

All member organisations were sent a survey via email. The terms of reference listed by Paul Gray CB were used to form the basis of the survey under the following headings:

- Claimant experience
- Face to face consultation
- Assessment criteria and process
- Reconsideration and Appeals
- Improvements
- Claimant satisfaction

- Additional information and evidence

The survey produced 120 responses, 81.20% from members and 18.80% from welfare rights advisers and organisations associated with NAWRA members.

Claimant experience

Question 2: Consider the PIP process. This includes making a claim, the daily living and mobility criteria used in the PIP assessment and getting a decision. Please describe:

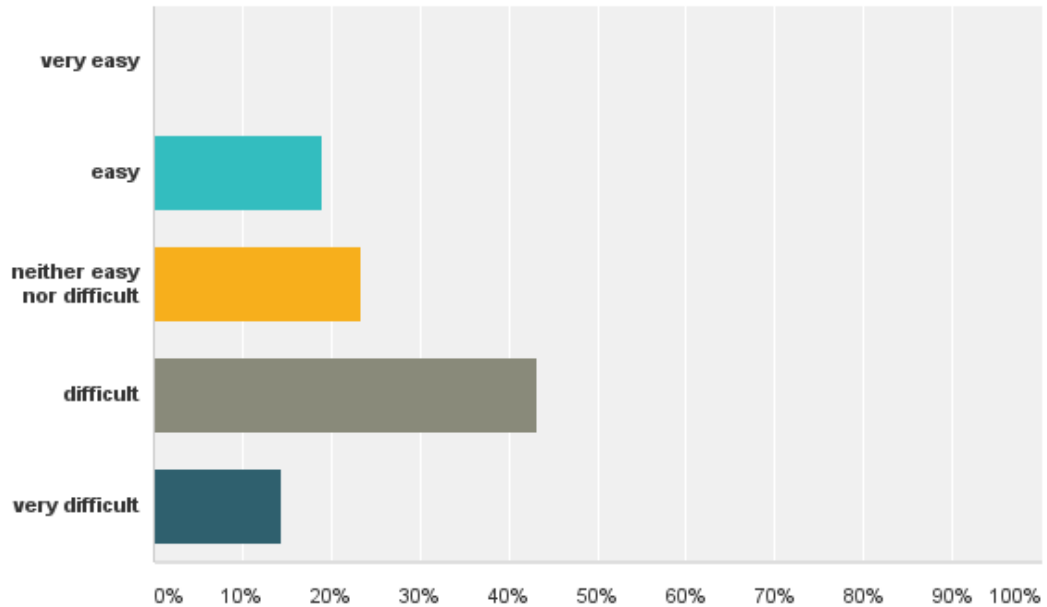
- a) **How easy is it for people to understand the whole process?**
- b) **How easy is it for people to make a claim?**

We asked members to tell us about their opinion of how easy the PIP process is to understand, rating between very easy to very difficult. Chart Q4 below shows the results. 57% of advisers who responded to our survey said that they found it difficult or very difficult for people to understand the PIP process. Only 18.92% said that the process was easy to understand.

Respondents felt that the 3 stage process, initial claim, PIP 2 and then the face to face consultation was difficult for claimants to understand. Many claimants were confused why a PIP 2 form needed to be completed as they thought the initial phone call was the claim. The fact that the process is fraught with delays is adding to the confusion.

Q4 In your experience how easy is it for people to understand the process?

Answered: 111 Skipped: 9



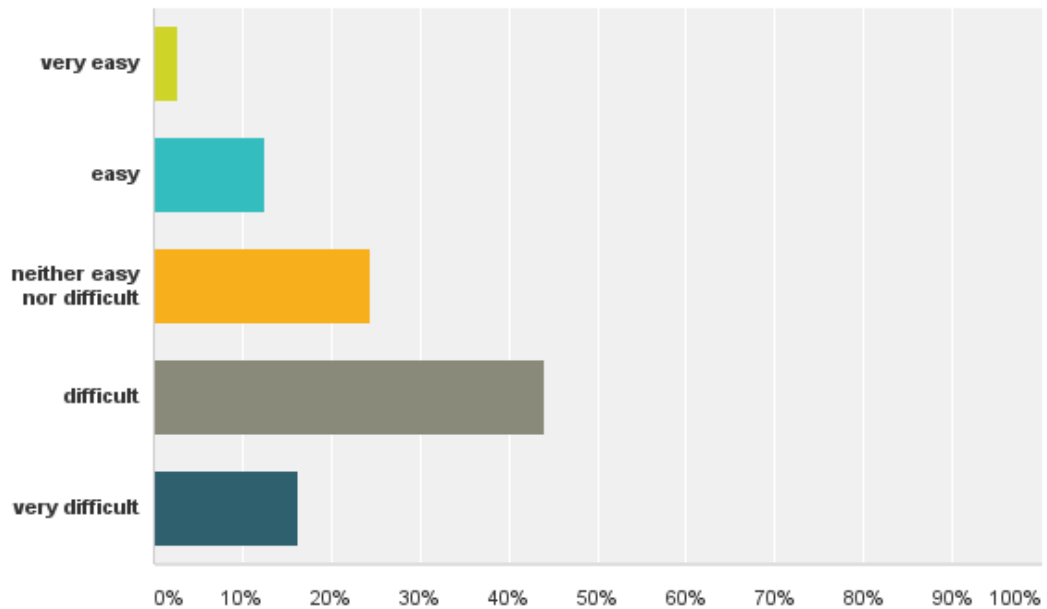
Report of claimants waiting for up to 26 weeks before being asked to attend a face to face assessment with no contact from the department in the meantime is a cause for concern. One respondent states:

“It is taking so long, customers make a claim and then go months and months without hearing anything. I have had customers who have applied and then not heard anything for 6-7 months so assume they have been unsuccessful and put in another claim thus cancelling the previous one and having to go through this lengthy process again”

Chart Q6 below shows how easy advisers feel it is to make a claim for PIP. Only 2.70% of those who responded to our survey said that they feel it is very easy to make a claim for PIP. In sharp contrast 44.14% said it was difficult and 16.22% said it was very difficult

Q6 In your experience how easy is it for people to make a claim for PIP?

Answered: 111 Skipped: 9



A big issue for members was that claimants were not fully prepared for the initial telephone call and did not have the information required ready to hand – not realising the amount of information that needs to be gathered at this stage. Many were concerned about the gathering of bank details at this stage and the lack of explanation about the process.

Picking up the telephone can be daunting for some people and can put some off making a claim.

Issues around call handlers asking intrusive and insensitive questions particularly around terminal illness and mental health were reported by many of our members. The script appears to be the issue here and we would suggest that DWP work with organisations such as Macmillan Cancer Support and MIND to improve the script and provide awareness training for staff.

All respondents who work with people with either mental health issues or learning disabilities reported that the process does not cater for their clients. The initial telephone call causes anxiety and confusion and is often off putting. Call handlers insisting that they speak to the claimant rather than their representative causes difficulties and delays.

“I work with people with mental health issues and the claims process even with practical assistance with the first telephone call can cause extreme anxiety and distress. People who

are already socially isolated and are either unable to or find that asking for help is not an option are bound to be put off at the first hurdle”

Members working in the “natural assessment” areas say that people currently in receipt of DLA are finding the transition from DLA to PIP confusing. Initial letters to current DLA recipients regarding the migration process are confusing and too long. Often advisers call the PIP line in order to initiate a claim for PIP only to be told that they need to request a supersession of DLA or vice versa. The general perception is that call handlers are also confused by the process which is only adding to the frustration of claimants and advisers.

“for new claimants it has been ok I think - fairly straight forward.....but DLA reassessment claimants they were getting letters 9 pages long!- much too confusing..”

Lack of transparency with the points system not being explained was an issue that the majority of our members were concerned about. Claimants are not advised about the point system until they receive the decision notice and find this confusing.

In regards to the application form feedback from advisers was that the form is easier to complete than the Disability Living Allowance. However the majority felt that an explanation of the point’s criteria needs to be included in the form for greater transparency and to aid claimants understanding of the qualifying criteria. This could be included in the accompanying notes or built in to the actual questions.

Face to face consultation

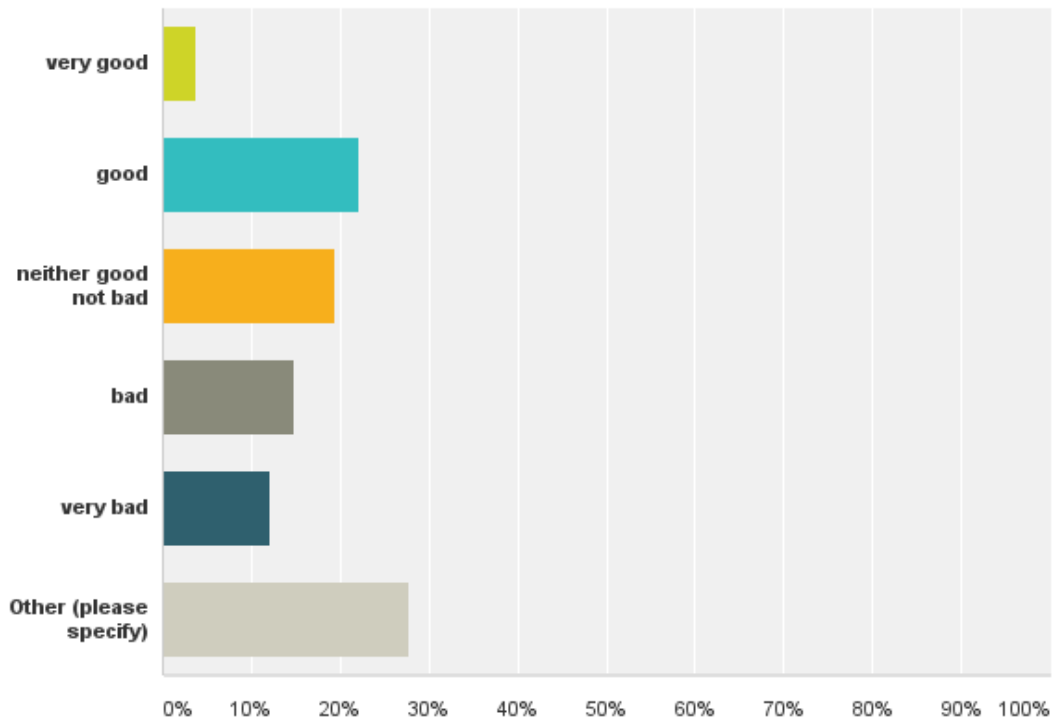
Question 3: Please tell us about the experience of having a face to face consultation with an Atos or Capita health professional.

We asked members to tell us about their experience of the face to face assessment. Although many did not have direct experience of attending a face to face assessment they were able to tell us about the experience reported to them by claimants and support workers who had direct experience.

The chart Q8 below shows that 22.22% of respondents say that they would describe that face to face experience as good. The 27.78% who chose “other” as their answer all concentrated on the delays that have been caused by the face to face assessment.

Q8 how would you describe the face to face consultation experience

Answered: 108 Skipped: 12



The vast majority of those members who responded to our survey express concern about the delays in the assessment process. Many reported clients waiting in excess of 6 months for a face to face assessment. Unfortunately members state that the majority of their service users are still waiting for their face to face assessment and so had little to report. However issues around suitability of venues and the distance claimants are asked to travel for an assessment has also raised great concern amongst advisers.

The lack of home visits is an issue for those who are housebound and appointments being cancelled at the last minute by Atos or Capita.

“The whole process can prove difficult for them as just having to telephone the call centre and give the first 18 pages of information via the telephone for P.I.P 1. Also they would not understand a lot of the questions. It is also wrong to be asked about terminal illness in the way the question is asked even if the person does not suffer from one it can still be distressing being asked that question. Then of course there is the P.I.P. 2. While advisers may welcome the new form (as it's simpler than a DLA form) the claimant may struggle with form completion and may not give all of the information required to qualify for the benefit. Then of course they have to wait 6 months or longer for a face to face and when they receive the appointment they then worry about it constantly until the day comes and they struggle to

get to an assessment centre miles away from where they live and don't even know where they are travelling to. They then have a least another 8 weeks before they are given a decision on their claim”

Further evidence

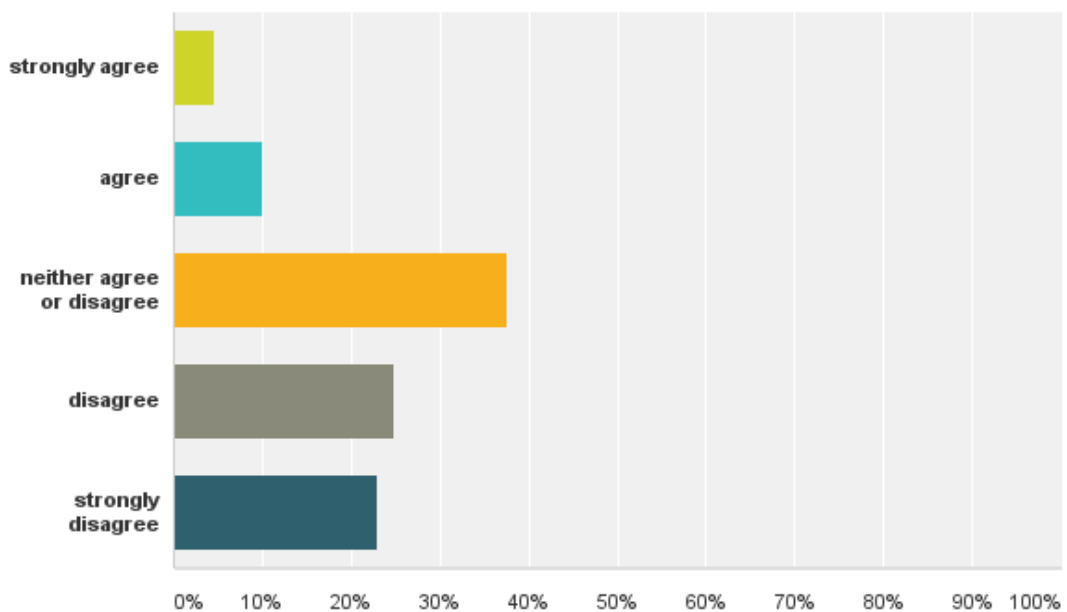
Question 4: Consider how further evidence is used in the PIP process. Please provide information about whether further evidence is being:

- a) Requested appropriately by Atos or Capita?**
- b) Provide in time?**
- c) Used appropriately and fairly to inform decisions?**

We asked members to tell us about their experience relating to the use of further evidence in the PIP assessment process. The chart below shows that over 47% of respondent’s state that they disagree or strongly disagree that evidence is being requested appropriately. In addition we asked if the evidence was being used appropriately and fairly. 14.02% of respondents state that evidence is being used appropriately whereas over 30% either disagree or strongly disagree that it is.

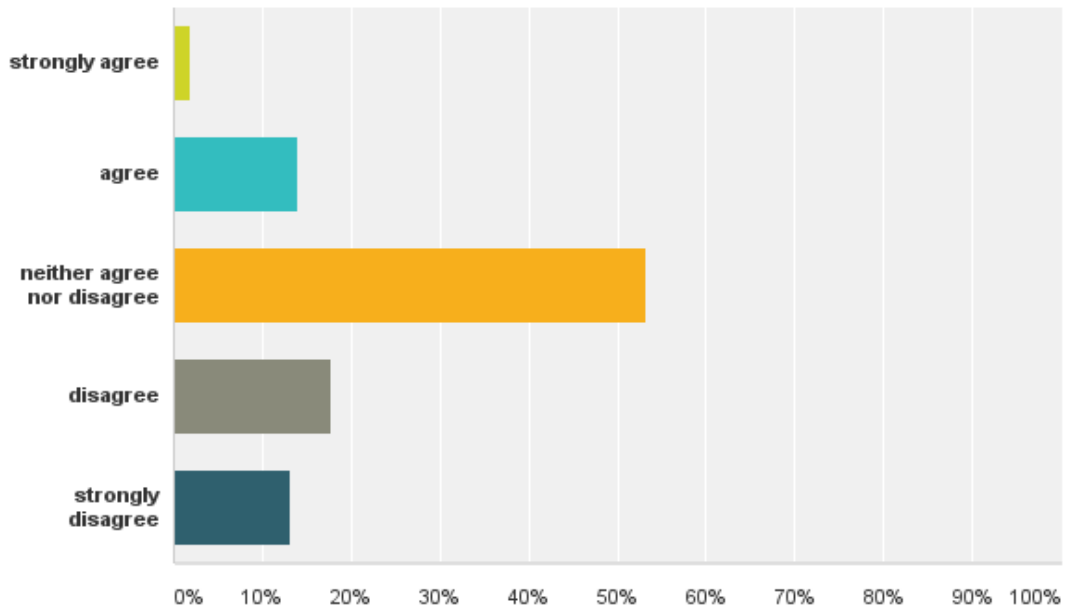
Q10 Further evidence is being requested appropriately

Answered: 109 Skipped: 11



Q11 Further evidence that is provided is used appropriately and fairly to inform decisions

Answered: 107 Skipped: 13



The lack of decisions made it difficult for members to offer a depth of experience however all respondents have had experience at some level regarding additional supporting evidence.

This is a typical example of the view of members. Evidence is supplied at the initial stage however this is often overlooked or disregarded by the DM or HCP. If evidence provided by CPN's, Social Workers, Consultant Psychiatrists and other support workers at the initial claim stage was given the appropriate weight then our members believe that this would reduce the numbers of claimants requiring a face to face assessment.

"Atos just ignore it and we have had to get our local MPs to intervene and get decisions made on the evidence alone. They do not seem to know how to evaluate good evidence. If they could take out the cases where it is obvious they qualify it might mean people are seen quicker by Atos. People are getting ill because of benefit processes and feeling that they are not going to be treated fairly. It does not encourage people to manage their lives and try work."

Those respondents who work with terminally ill claimants have found that delays have been caused because the HCP has questioned the need for a DS1500. This is cause of great concern for our members who report that this is happening frequently.

In one such case a terminally ill claimant was given a DS1500 however the HCP questioned the diagnosis and requested another DS1500 causing long delays, unfortunately this claimant died within 6 months of the date of claim.

Members are concerned that these delays will mean that some terminally ill claimants will die before they receive a decision on their PIP claim.

Assessment criteria and process

Question 5: Where you have evidence of any of the following please describe how effective the PIP assessment is:

- a) For people with one condition?**
- b) For people with more than one condition?**
- c) For people with conditions that change (fluctuating conditions)?**
- d) For terminally ill people?**
- e) In identifying whether someone is eligible for the standard rate or the enhanced rate?**
- f) In identifying those eligible for the mobility component of PIP as a result of needs arising from their condition?**

The chart Q13 and table below show how effective respondents feel that evidence is used when making decisions in relation to the above claimant groups. We asked respondents to rate from 1 to 5, 1 being very effective and 5 very ineffective.

The general consensus of member is that when assessing people with one condition the HCP appear to be dealing with these appropriately. However when dealing with claimants who have more than one condition some difficulties have arisen with HCP's, who specialise in a specific area, have focused on one condition which is not always the cause of primary difficulty for the claimant. We believe that HCP's needs to establish the primary condition that causes the most difficulties and address all conditions equally.

Claimants who have fluctuating conditions are a more complex area that HCP's and DM's have difficulty with. Often when assessing these claimants the HCP or DM will focus on the good days or the positives which are due to services provided to the claimant that help with managing day to day living. The HCP need to ensure they establish the correct information and fairly represent the claimant, additional evidence is very important.

There have been improvements with terminally ill claimants however members feel that there are still more improvements to be made. As previously stated issues appear to be training of telephone staff and improvements to the script.

Generally respondents felt that evidence provided in relation to terminally ill claimants was taken in to account however many reported issues with some HCP as described in the answer to question 4.

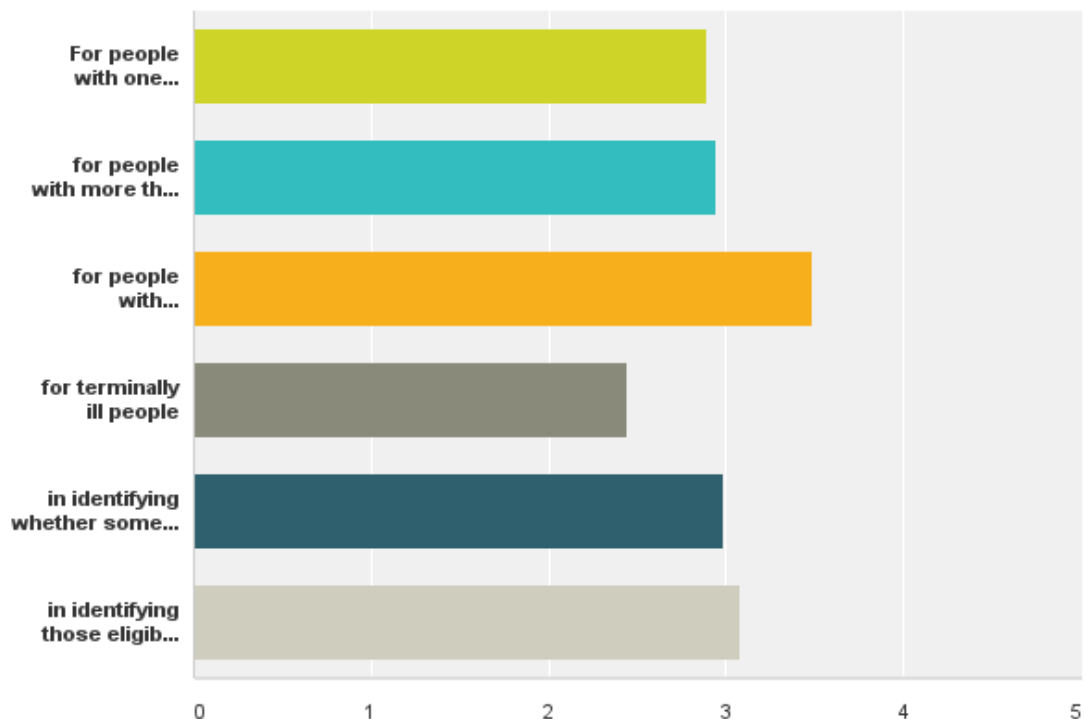
“As I deal only with cancer patients the special rules process has worked well but still takes longer than a DLA claim. I had one client refused under the Special Rules. It took 3 months to have his benefit awarded and he died a few weeks later. Evidence we send in does not seem to be used to speed up the decision making process.”

“Macmillan team do many claims for terminally ill and after poor start now get quicker result as providing DS1500. Evidence of fluctuating condition appeared to be ignored in the ATOS medical - from papers received for appeal. Also not considering "reasonable" test.”

Members didn't feel that additional evidence provided helps determine the decision whether standard or enhanced rate is awarded. The general perception is that DWP, Atos and CAPITA are reluctant to accept additional evidence provided regardless of the source.

Q13 Where you have provided evidence of any of the following please describe how effective the PIP assessment has been

Answered: 82 Skipped: 38



	very effective	effective	Neither effective Nor ineffective	ineffective	very ineffective	Total
For people with one condition	2.67% (2)	32.00% (24)	46.67% (35)	10.67% (8)	8.00% (6)	75
for people with more than one condition.	2.78% (2)	29.17% (21)	47.22% (34)	12.50% (9)	8.33% (6)	72
for people with fluctuating conditions	0.00% (0)	14.29% (10)	38.57% (27)	31.43% (22)	15.71% (11)	70
for terminally ill people	27.27% (18)	24.24% (16)	33.33% (22)	7.58% (5)	7.58% (5)	66
in identifying whether someone is eligible for the standard rate or the enhanced rate	0.00% (0)	31.08% (23)	44.59% (33)	18.92% (14)	5.41% (4)	74
in identifying those eligible for the mobility component of PIP as a result of needs arising from their condition	2.78% (2)	22.22% (16)	47.22% (34)	19.44% (14)	8.33% (6)	72

Reconsideration and Appeals

Question 6: In your experience what are the reasons for people asking the DWP to look again at their PIP decision?

In most case claimants are unhappy with the decision and have difficulty understanding why they have not met the criteria. Claimants challenge decisions when they don't agree with the outcome of the face to face assessment or are unsure why additional evidence they have provided has not been taken in to account.

Until a decision is issued claimants are unaware of the points criteria and find this difficult to understand and work out why they have or haven't scored specific points. By requesting a Mandatory Reconsideration (MR) they are hoping for a more detailed explanation.

Members are concerned at the delays in the decision making process and lack of a time limit for a MR decision. This is adding to delays which are causing frustration and financial hardship.

Question 7: In your experience what are the reasons for people making an appeal to Her Majesty's Courts and Tribunals Service (HMCTS)?

A claimant appeals to Her Majesty's Courts and Tribunals Service (HMCTS) for the same reasons they request a Mandatory Reconsideration (MR).

Once again members are concerned at the delays in the decision making process. This is adding to delays which are causing frustration and financial hardship. Members are concerned that the number of PIP appears are artificially low due to lack of decisions being made. According to the DWP statistics issued in June 2014 less than 25% claims were decided upon.

Due to delays in the assessment process not many member have had experience at the appeal stage. Those who have experience at this stage state that the main reason people are appealing is because they are unhappy that further evidence supplied at the MR stage has not been taken in to account.

Improvements

Question 8: What has been your experience of the time it takes from making a claim to getting a decision?

When PIP was initially designed it was expected that the process from claim to decision would take between 12 – 15 weeks. Our member report that claimants are routinely waiting up to 26 weeks for a face to face assessment and then an additional 8-12 weeks for a decision to be issued. End to end our members are reporting case that are taking 9 – 12 months to reach a resolution.

Where a MR is requested and a subsequent appeal is submitted the timescale is extended considerably.

Special Rules cases are much better although we find that these cases are still taking 6 to 8 weeks for a decision however this is still significantly longer than a claim for DLA would have taken.

The main delay appears to be with the face to face assessment. This could be significantly reduced by increasing the number paper based assessments where evidence supports the claim. Additionally HCP may contact GP, Consultant, SW etc in order to obtain additional evidence where it is appropriate thus reducing the number of face to face assessments.

Question 9: What has been the impact of this?

Members are concerned about the length of time it takes from claim to decision which is totally unacceptable and is causing severe hardship for some of the most vulnerable people in society. PIP, as with DLA, is often an essential part of a disabled person's income. Vulnerable people are being left living on a low income and are often unable to afford the additional costs that their disability brings such as care costs, additional travel expenses,

heating and dietary costs. Many have had to rely on Discretionary Housing Payments in order to afford rent costs.

“The length of time decisions are taking is having a really negative impact on our clients. Examples are: - People dying before they receive their PIP award. - People not being able to make a decision to not work for a while to care for an ill partner, and be able to claim Carers Allowance. - The impact of not getting the money to cope with their extra needs when they need it. The impact of not getting the extra money on their other means tested benefits”

Question 10: Consider the whole PIP process. This includes making a claim, going to the face to face consultation, the daily living and mobility criteria used in the PIP assessment and getting decisions. What improvements could be made? Please explain how these improvements would help.

NAWRA believe that the whole process needs accelerated with better liaison between the DWP and Atos/Capita and better liaison with advice agencies. This can be achieved by:

- More paper base assessments where additional, appropriate evidence is submitted leading to less face to face assessments therefore speed up the process.
- The time limit for DWP to complete mandatory reconsideration should be specified and laid down in legislation so that vulnerable people are not left to bear the extra costs of their disability without support.

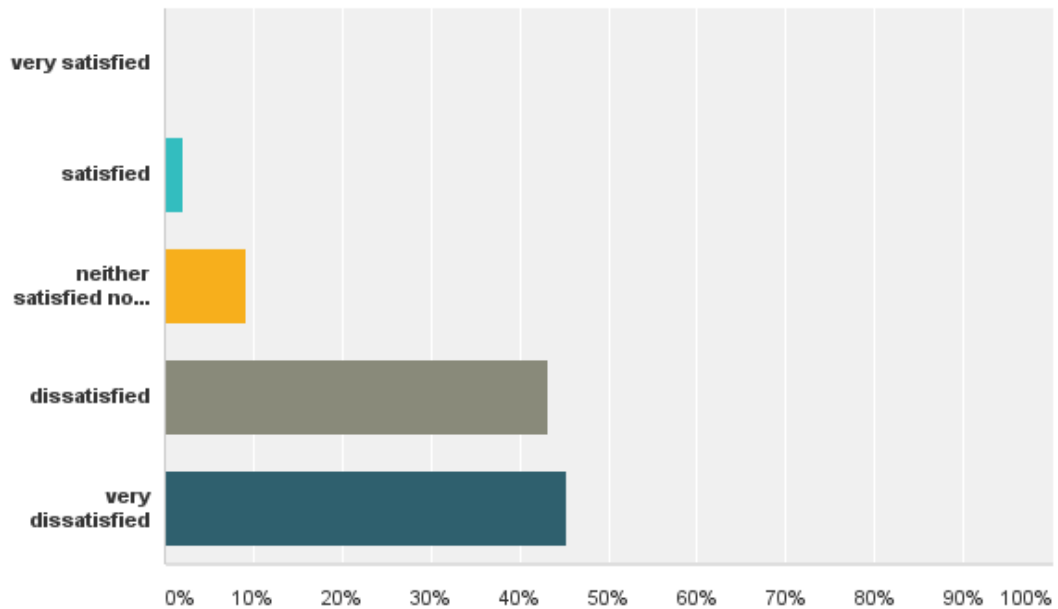
Claimant satisfaction

Question 11: In your experience how satisfied are you with the overall process? Please tell us why you feel this way.

We asked members how satisfied they are with the overall process, 88.66% of respondents stated that they are either dissatisfied or very dissatisfied with the overall process. Only 2.06%, of respondents reported that they are satisfied with the overall process.

Q18 how satisfied are you with the overall process?

Answered: 97 Skipped: 23



The reasons respondents gave were:

- Length of time the initial phone call take
- The length of time taken to get a face to face assessment
- The apparent disregard of additional supporting evidence supplied at the initial claim
- Claimants being asked to attend a face to face assessment when it is not appropriate and evidence has been supplied to support this
- Distance claimants have to travel for face to face assessment
- Inflexible process
- Lack of communication

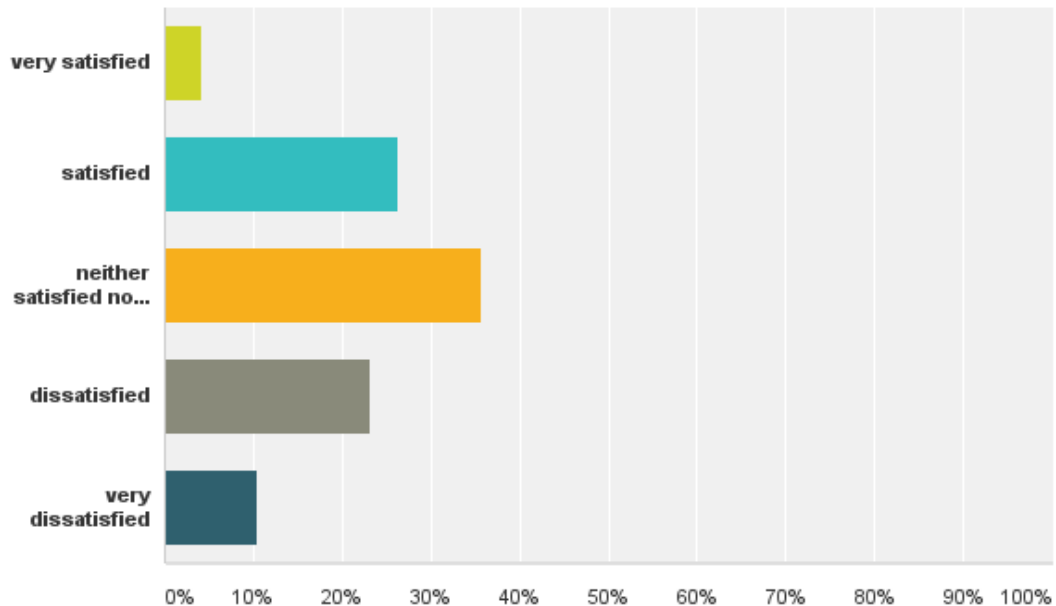
The delays in decisions being issued are the main reason members are dissatisfied with the process. Members have evidence of claimants waiting 9 – 12 months for decision and this is totally unacceptable.

Question 12: Consider the decisions made on PIP claims. How satisfied are you that these are being made appropriately and fairly? Please tell us why you feel this way.

The chart Q20 below shows a variety of opinion amongst members when asked if they feel that decisions are being made appropriately.

Q20 How satisfied are you that decisions made on PIP are being made appropriately and fairly?

Answered: 95 Skipped: 25



The major reason for this is that many respondents are in the position where the majority of their service users are still waiting for decisions. Because of these delay it is difficult to judge if the decisions made so far are a true reflection. It is also difficult to judge how the criteria is being applied to specific claimant groups such as mental health, learning disabilities, claimants with conditions such as ME.

Members have reported positive results however they state that some of the decision making is inconsistent within certain claimant groups and some DM's are applying the criteria in different ways.

Additional information or evidence

Question 13: Please provide any additional evidence or information you think might help.

We understand that the policy intention behind a 4 week run on of DLA was to protect those people who would lose out by receiving a lower or no award of PIP following their "natural assessment".

However NAWRA members have dealt cases where those who have received a higher award of PIP have lost out significantly. Many of these cases have been terminally ill claimants. Due to long delays in the process claimants are not just losing out on the 4 week increase they are losing out in most cases on at least 6 months increase as PIP is only paid 4 weeks after the date of the decision. This also has a knock on effect on means tested benefit such as Income Support and Housing Benefit.

In an area undergoing “natural assessment” claimants and advisers are faced with the perverse situation where two people may have a change of circumstances and one received an increase from the date they report it as they are in a non “natural assessment” area and the other does not receive any arrears as they are within a “natural assessment”.

It seems then that any limited transitional protection afforded to PIP "losers" from the 4 weeks seems then to be financed by a tax on the "winners" and in many cases the terminally ill.

NAWRA are sure that it cannot be the intention to penalise severely disabled people and those with at terminal illness in this way. We would welcome any review in to this particular provision within the regulations.

In addition NAWRA would like to make the following recommendations:

1. Increase the number of paper based assessments where additional, appropriate evidence is submitted leading to less face to face assessments therefore speed up the process.
2. Consideration is given to the time limit for DWP to complete mandatory reconsideration being specified and laid down in legislation so that vulnerable people are not left to bear the extra costs of their disability without support.
3. Improvements are made to the script used by call handlers dealing with the initial claims, training/liaison with groups such as MIND and Macmillan Cancer Support would be invaluable.
4. Consideration is given to an alternative format for submitting an initial claim.
5. Improve communication with claimants; the letters are too long and complicated. Due to delays claimants are often left not knowing where in the process their claim is. We would welcome regular update letters being sent during the process giving accurate timescales. NAWRA would also welcome improved communication with advisers and facilitate communication with Atos and Capita by routinely passing on any consent forms submitted with PIP2 forms.
6. To improve transparency and trust NAWRA recommend that DWP produce regular reports regarding performance with regards to the processing of PIP claims.