

## **First independent review of the Personal Independence Payment assessment** **Response from Headway – the brain injury association**

### **Introduction**

Headway, the UK-wide charity that supports people affected by brain injury, welcomes the opportunity to contribute to the first independent review of the Personal Independence Payment (PIP) assessment.

Headway is a service user-led organisation, representing people with acquired brain injury (ABI) across the UK and Channel Islands. We have extensive experience of supporting people who claim and rely upon Disability Living Allowance (DLA) and PIP, through our network of groups and branches and other frontline services such as our national helpline.

Responding to this consultation has been a challenge as our research shows a high percentage of PIP claimants have been in the claims process for many months, with little or no information on the status of their claim. As such it has been difficult to gather information from a sufficiently large group of claimants who have been through the process. The evidence we have been able to gather, however, is included here along with some useful feedback from our members.

Given that the standard claim is currently taking a number of months (some claimants reported waiting times of over a year), our first recommendation is that the DWP, Atos and Capita quickly increase the resources dedicated to these assessments. This will help prevent the current situation where people who require this essential income are having their independence limited.

## **Question responses**

### ***Question 1a***

This response is on behalf of Headway – the brain injury association. Information has been gathered from members and stakeholders of the charity via our Facebook page and our online discussion forum. We have also discussed the situation with experienced welfare rights advisors who support people with brain injury through the assessment process.

### ***Question 1b***

Headway is a service user-led organisation that supports people with acquired brain injury, many of whom have claimed or intend to claim PIP.

### ***Question 1c***

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## **Claimant experiences**

***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?***

The claim process itself is relatively easy for people to understand. The structure of making the initial claim, completing a form and receiving a decision is familiar to people. This familiarity and consistency will be useful to those DLA claimants who are being reassessed for PIP from next year.

There is however a general lack of awareness of the eligibility criteria, causing many people with cognitive disability to feel that PIP focuses more on physical disability and that they would not qualify should they apply. There is a lack of awareness of the 'reliably' criteria, so when people can do an activity they feel unable to claim this benefit, despite not being able to carry it out reliably, repeatedly, safely and in a timely manner.

Our member said:

*"The list for PIP is not dissimilar to DLA and a lot of it is washing/bathing (I have a bath step, shower stool and handrails), dressing, eating and drinking, toileting etc all of which I can do...I am still not sure that the assessment gives a way to highlight the impact of my executive function, cognitive and emotional/social/behavioural issues sufficiently to be able to get PIP."*

We recognise that PIP's scoring criteria does allow many aspects of cognitive and behavioural problems to be accounted for. However, the DWP needs to work on better ways to disseminate this information to claimants, including guides on how to fit various complex information processing/cognitive symptoms into the form (please see the appendix for a list of the common symptoms of brain injury).

Many people with brain injury are finding the physical act of completing the form difficult due to its length.

Members said:

*"We completed Hubby's form a month ago – it took best part of a day and I wrote most of it as he struggles with fatigue."*

*"The form takes so so long to fill out and I was lucky to have a friend sit with me for hours and days to get through it."*

It is clear that most people with brain injury benefit greatly from having someone to support them in completing the form. As such we would suggest that more government funding should be available to welfare rights advice services. This includes services provided by local authorities, the Citizens Advice Bureau and, for complex conditions such as brain injury, Headway.

There was some concern raised that the application for PIP has changed such that claimants can no longer pick up a form from their local advice centre, post office, JobCentre Plus, for instance, and this may deter some people from applying.

## **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 have had mixed feedback about the consultations, however in general the experience has been much more positive than with the WCA assessments. Some feedback indicates that the assessors are much more willing to ask for more information around a particular activity and engage with clients.

However some people have expressed concerns about aspects of the assessment, with crude tests such as reading sentences on a card, stretching out arms and overly-simplistic memory tests. Brain injury is a complex, fluctuating condition that can only be adequately assessed by specialist medical professionals. It is of concern that in some cases PIP assessments still do not recognise this.

The WCA process has been heavily criticised for similar failings, leading to a high level of successful appeals from claimants, at great cost to the public purse and unnecessary suffering to the claimants themselves. It is vital the DWP does not repeat the same mistake with PIP.

As discussed above, a key issue has been the long wait from returning the form to receiving the face-to-face consultation. Some members have reported that on enquiring about the delay, they have been offered an assessment outside their area where waiting lists are shorter. This may be a positive step for some claimants, but would be impossible to take advantage of for the most vulnerable people, for whom mobility is an issue. Clearly achieving short waits consistently across the country should be a high priority.

Encouragingly, it seems assessors are explaining the next steps to applicants and their role in the decision-making process, although currently the wait from assessment to decision is still unacceptably long. Some claimants have been told a decision will be made 'in a few weeks', and have subsequently waited for months to hear the outcome of their claim.

Clear, realistic timescales must be given to claimants. The emotional and psychological effects of brain injury, including anxiety, obsessive behaviour and depression, mean that uncertainty can cause disproportionate stress to survivors that could exacerbate their condition.

## **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) Provided on time?***

***c) Used appropriately and fairly to inform decisions?***

Given the low number of people who have received a PIP decision due to delays in the application process, we do not have sufficient information to answer this question at this time.

## **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?***

Given the low number of people who have received a PIP decision due to delays in the application process, we do not have sufficient information to answer this question at this time.

## **Reconsideration and appeals**

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

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

We will answer questions 6 and 7 together.

As discussed above, there are very few claimant journeys to draw on and provide evidence to this question. From the claimants and advisors we have spoken to, there is still a general perception that the mandatory reconsideration offers at best a slim chance of avoiding having to conduct a formal appeal.

However, offering claimants an opportunity to avoid a formal appeal with much longer associated delays is a positive step. We do not have any useful statistics on the amount of time it is taking to reach a final decision following a request for reconsideration, but we feel that this should be achieved in as short a time as possible to ensure potentially vulnerable claimants are not waiting unnecessarily for their benefit.

The HMCTS tribunal has received some positive feedback, however the decisions that are overturned at both this and the mandatory reconsideration phases indicate

that the assessment process is still getting things wrong. This is the primary reason for a reconsideration and/or appeal being requested.

## **Improvements**

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

This has been discussed in detail in various sections of this consultation response. The time claimants have been waiting is clearly unacceptable, and has typically ranged from six to 12 months.

In August 2014, claimants said:

*"We heard nothing for months and when I phoned I was told that yes, they did have the form but it was a case of wait in line because of the backlog. Having the same response many times I finally contacted our MP and this was then dealt with without an assessment. So it took just under a year."*

*"The waiting time for the process once the forms are sent back is ridiculous. In the mean time not being able to return to work fully and husband out of work is crippling us financially."*

*"I've been waiting since April, my neurological condition has left me with muscle deterioration and I'm now disabled."*

*"Having to wait six months for the process is crazy. Husband had strokes December and March and have not been able to claim a penny... how we have kept going is beyond me and still we waiting. Completely shattered and struggling!"*

*"One year after applying...nothing. Constant chasing and they all say on the other end of the phone that it is being processed and may take another few months."*

### ***Question 9: What have been the impacts of this?***

The most obvious impact is that people who rely on PIP to allow them to achieve some level of independence are unable to access the benefit. This can leave claimants and their families with very little income, and without access to essential 'passported' benefits and schemes such as Motability. PIP was set up to 'help with some of the extra costs caused by long-term ill-health or a disability' (gov.uk), and claimants waiting for decisions are unable to access this vital support.

For people with effects such as memory problems, a long period from completion of the form to assessment can be difficult. The act of completing the form can be difficult in itself, and to have to go through this again, recalling and recounting the effects of a complex condition some months down the line, puts undue pressure on

the claimant. Claimants who may already have a range of psychological difficulties and are struggling with their daily life may become extremely distressed by the uncertainty and financial difficulties caused by these delays.

We have heard of cases where DWP decision makers contact claimants by telephone some time after the assessment, to see if anything has changed with their condition. This question could be difficult or impossible for a claimant with brain injury to answer, and could lead to poor decisions being made. This practice should only be used where a support worker or family member is present to support to claimant in answering such questions, and decision makers doing this need to be aware that a claimant with brain injury may not always be able to describe their condition accurately.

The long timescales for assessment are particularly worrying given that existing DLA claimants will be reassessed from next year, and the waiting times must be brought down to acceptable levels before this occurs.

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

Initially, claimants need improved access to information about the benefit, making it clear that it can be claimed by people with cognitive disabilities. This would help them to make a judgment over whether PIP would be suitable for them, and make a more informed decision over whether to claim.

There also needs to be increased provision of support for claimants to complete their form, attend the assessment and manage the appeal if necessary. This has been eroded due to changes in the legal aid scheme, but having appropriate initial guidance helps the DWP to make the right decision. This in turn reduces requests for reconsideration and appeal, freeing up resources to deliver better assessments and decision making.

We appreciate that the form needs to examine a number of different aspects of daily life so needs to be comprehensive, but it should be accompanied by clear guides to help people with complex, less visible conditions to explain their issues.

We would also request that assessors have awareness of the condition that the claimant has indicated. Accurately assessing a person with brain injury is a specialist task, and while we are encouraged by early reports of assessors taking time to engage with the claimant, it can take a great deal of awareness to identify the often hidden effects of a brain injury that can cause severe issues with daily activities. Fatigue can cause dramatic fluctuations in a person's ability after brain injury, and assessors need to be aware that a simple 'snapshot' of the claimant's performance in the assessment may not be representative of their real-life ability. They need to

question claimants on issues such as this, as the answers on the form may also not describe this accurately.

The aim is to make sure most initial decisions are correct, meaning claimants can achieve a higher level of independence and engage with society as much as possible. Again this would also reduce the workload due to reconsiderations, appeals and re-applications.

Further training must be given to ensure assessments are not simply 'mechanical' tick-box exercises, and take a holistic approach to a person's disability.

### **Claimant satisfaction**

Questions 11 and 12 questions are primarily for individual claimants' responses so we have not provided a response in this consultation, however we have included information on claimant satisfaction in the above answers.

### **Additional information or evidence**

Given the situation described, where relatively few people are currently claiming PIP, we do not have additional evidence to give at present. However we would welcome the opportunity to actively engage with the DWP and future independent reviews, with the goal of improving PIP for people with brain injury.

Despite the limitations and issues in PIP, there are some promising signs that the assessment process is making more effort to properly assess people with complex conditions. However we are only too aware that this is a 'honeymoon period' for the benefit in which there is a great deal of scrutiny, and continuing improvements must be made as we approach the complete replacement of DLA in 2017.



## **Appendix 1: Key facts and statistics**

### **Acquired brain injury**

This includes all admissions for head injuries, strokes, brain tumours, meningitis, encephalitis, hydrocephalus, anoxia, CO poisoning, abscess and hyponatraemia.

- 1 million - Minimum estimate of people in the UK living with long-term effects of brain injury
- 558 - UK residents per 100,000 sustaining a brain injury
- Every 90 seconds - Someone is admitted to hospital in the UK with acquired brain injury
- 353,059 - UK admissions to hospital with acquired brain injury in 2011-12
- 661 - Northern Ireland residents per 100,000 sustaining an acquired brain injury in 2011-12, the highest rate in the UK

### **Head injury**

These indicate traumatic brain injury, ranging from minor brain injuries to severe injuries causing long-term disability.

- 213,752 - Total UK admissions to hospital for head injury in 2011-12
- 169,673 - UK admissions to hospital with a non-superficial head injury in 2011-12
- 33.5% - Increase in UK head injury admissions in the last decade
- 10,000 - 20,000 - Number of severe traumatic brain injuries per year in the UK
- 2x - More likely for men to sustain a traumatic brain injury than women
- 15-24 year old males and over 80 year olds - Groups most at risk of traumatic brain injuries

### **Effects of acquired brain injury**

#### **Behaviour and personality**

Anxiety, depression, loss of motivation, difficulty controlling anger, and impulsivity.

#### **Cognitive**

Problems with memory, attention and concentration, low tolerance of noisy or stressful environments, loss of insight and initiative.

#### **Physical**

Loss of co-ordination, muscle rigidity, paralysis, epilepsy, difficulty in speaking, loss of sight, smell or taste, fatigue, and sexual problems.

- Initial diagnosis of severity of injury is not a reliable indicator of long-term problems
- Relationships with family and friends can be placed under immense strain
- Relatives report that the ten most difficult problems are personality changes, slowness, poor memory, irritability, bad temper, tiredness, depression, tension and anxiety, rapid mood changes, and threats of violence

## **About Headway**

Headway - the brain injury association is a registered charity (no 1025852 / SC039992) and a company limited by guarantee (reg. no 2346893).

## **Improving life after brain injury**

Headway is the UK-wide charity that works to improve life after brain injury.

Through a range of frontline services run from its Nottingham base and via a network of more than 100 groups and branches across the UK, it provides support, services and information to brain injury survivors, their families and carers, as well as to professionals in the health and legal fields.

A brain injury can have devastating consequences for individuals and their families, affecting every aspect of life. Although we all think 'it'll never happen to me', a brain injury can affect anyone at any time. When it does, we're here to help.

## **Frontline services**

- A freephone nurse-led helpline (0808 800 2244, [helpline@headway.org.uk](mailto:helpline@headway.org.uk))
- An emergency fund to assist people dealing with the financial implications in the immediate aftermath of a brain injury
- Headway Acute Trauma Support (HATS) nurses to support families whose loved ones are in the acute stage of care following brain injury
- A comprehensive award-winning website containing information and factsheets on all aspects of brain injury
- An award-winning range of booklets and factsheets designed to help people understand and cope with the effects of brain injury
- A network of more than 120 groups and branches that provide physical, cognitive and social rehabilitation and support to individuals and families
- An accreditation scheme for approved residential homes, rehabilitation units and respite facilities specialising in ABI
- A directory of over 170 specialist brain injury solicitors, to help people get the legal advice they need after brain injury
- Training courses to improve knowledge and understanding among professionals working in the field of brain injury.

## **Behind the scenes**

- Campaigning and lobbying for better support and resources to be made available to people affected by brain injury, speaking out against government policies and social and health care changes that are not in the best interests of people affected by brain injury
- Raising awareness of brain injury and its effects in the national media through regular television interviews, features, dramas and documentaries; via newspaper articles and interviews in magazines; and through thought-provoking, hard-hitting debates on radio programmes