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Second independent review of the Personal Independence Payment 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 second 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.

In compiling this review, we sought feedback from our groups and branches across the country, who directly support people with brain injury who are often experiencing issues with the benefits system. We also informed our members via our social media channels.

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Question responses

3. In your experience what types of further evidence do claimants send in as part of their claim?

Our members send in a range of further evidence alongside their claims, such as lists of prescriptions, appointment letters, letters from specialists following clinic appointments and letters from Headway support workers.

4. In your experience what further evidence does Atos/Capita request on claimants' behalf? Is this requested on time and used appropriately and fairly?

None of the people we spoke to have any record of Atos/Capita requesting any specific further evidence, although they may write to the claimant's doctor as specified on the form.



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5. Is it clear what further evidence is being asked of claimants? Please briefly explain your answer.

It seems clear that further evidence is not being requested when it should be, and when it would help the claim. It is important to note that in the case of many people with brain injury, cognitive impairment may make it difficult for the claimant to know what evidence to send alongside their application and gather it together, so it must be Atos/Capita's responsibility to request this on their behalf.

6. From your understanding, when claimants submit their claim how important do they think it is to submit further evidence? Please briefly explain your answer.

It is vitally important that claimants submit further evidence, however the reasons for this are not explained. There is a combination of factors related to people with brain injury that make it especially important to provide further evidence, and this should be explicitly stated on the form.

Firstly, many claimants find it difficult or impossible to describe the effects of their brain injury on the form. Brain injury is not 'black and white', and projecting its wide-ranging effects on to very tightly defined activities is a complex cognitive task in itself. For this reason, it is often not the claimant who suggests and supplies further evidence, rather it is their partners or close family members.

For those without this support, the claims process is difficult and unfair and could lead to people being discriminated against by the system. Again, Atos/Capita should be taking the lead in requesting further evidence in order to build up an accurate picture of the claimant's disability, however we have no evidence that this is happening.

Secondly, people with brain injury place their trust and reliance on a number of non-specialist healthcare professionals when applying for PIP. With key assessments and reports being carried out by the Atos/Capita healthcare professional and their GP, many of our members feel that there is very little input from specialists who are qualified to assess and understand the effects of a complex neurological condition. The specialist evidence becomes the only way to provide this information through the application process. We would suggest that it becomes a requirement that Atos/Capita seek specialist evidence for all brain injury-related claims, commissioning it on behalf of the claimant if necessary.

At present, when people do submit evidence and present their case at assessment, it is not always being taken into account:

"They did not take into account my severe hip pain, documented by many clinicians, on walking any distance nor the fact I am unsteady on my feet.



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"My benefits advisor told me that she knew no one who had submitted more supportive information than me. I had supportive letters from my GP, MP, Welsh Assembly member, Cardiac Nurse, Consultant in Neurorehabilitation, physiotherapist, prescription, photos of my legs with and without splint, copies of brain scan, Headway, paramedic statements from two recent falls at homes well as information regarding a recent house decant as the council levelled the floors in my bungalow because of my frequent falls." - Headway member

7. Are there any barriers for claimants in providing further evidence? Please provide examples.

The most common barrier for our members is, as described above, a lack of specialist input in the claims process.

Many people with brain injury, which is a long-term condition, see a specialist very rarely if at all. They may be on a 'maintenance programme', seeing their GP occasionally to review medication and lifestyle, but little else. Some people may never see a doctor, but live with the debilitating effects of their condition.

This makes sourcing evidence extremely difficult - claimants feel they have no options in this regard, as a letter from a hospital consultant that is many months or years old may be ignored, and there is nobody to turn to for an updated report.

As stated above, we would suggest that it is the responsibility of Atos/Capita to ensure that each claimant has a recent, current specialist assessment to act as evidence for their claim. While this may be expensive to administer, there would be a cost saving in increasing the number of decisions that are right first time, and improving people's chances of using PIP to increase their independence.

8. In your experience, when claimants go through the appeals system do they submit further evidence at this point? Why?

It is felt that there is much more opportunity to submit further evidence at the appeals process, and the types of evidence that may be considered are clearer to claimants and the people supporting them.

We believe the appeals process is a more transparent and fairer part of the applications process, however the target must be to get more decisions right first time. The high level of successful appeals, particularly for complex conditions such as brain injury, demonstrates that the initial assessment process is not currently fit for purpose. We are hugely concerned that many claimants will not have the emotional or cognitive ability to go through a distressing legal process to challenge their initial incorrect decision, so genuine claimants are being denied this key to independence.

Data sharing

We have no comments to submit in answer to these questions.

Claimant experience

12. From your experience, how could the PIP claim process be improved? Please provide examples or suggestions.

Brain injury is often described as the 'hidden disability'. While many people may have physical effects such as problems with movement, balance, coordination, sight and hearing, for many this not the case.

Many more people with brain injury experience a wide range of cognitive, emotional and behavioural effects that make carrying out daily living tasks extremely difficult. These effects can make even the act of applying for PIP next to impossible and a high level of support is essential.

As described above, we feel claimants struggle because of a lack of specialist input during the claims process. We feel that in order to accurately assess people with brain injury, either the Atos/Capita assessors should be neuro-professionals, or they should request this where it is missing. If a claimant has no recent neurological/neuropsychological assessment on file, this should be commissioned as part of the claims process.

The problems are also evident on the application form, where it is very difficult to explain the effects of a brain injury. For many people, they may feel that because they are able to complete a task they must tick 'yes', however a lack of insight or simply a positive outlook can make it impossible for them to identify that in reality, due to the complex effects of brain injury including fatigue, they cannot complete it safely, repeatedly, reliably and/or in a timely manner.

This common problem for our service users must be identified and taken into account by the Atos/Capita assessors. A brain injury diagnosis should be a 'red flag' that the application needs to be investigated more thoroughly, and the way the claimant presents on the form and in the face-to-face assessment may not be truly representative.

"When they receive the form its very size is problematic and causes anxiety. Fear of making a mistake in completing the form, even when being completed by someone without a brain injury, can be very debilitating." - Benefits and Training Officer, Headway Ayrshire

"Recently one of our service users was declined his PIP and it said in the report that he had no cognitive impairment. He most definitely does and we do not understand how this decision was made. It was again a physio who did the assessment. He is a gentleman with the 'hidden' injury. He was on DLA and cannot understand why he



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has been declined PIP when his injuries have not changed, in fact his anxiety is now worse. I told him that the criteria is slightly different and this case is now going to an appeal." - Carer Support Service, Headway Bristol

"My experience of the PIP process has been harrowing, fearful and has impacted greatly on my mental health and my relationship with my partner. The interviewer who came to my home informed me she did not know anything about brain injury but was qualified in nursing and midwifery." - Headway member

"Claimants very often will try to answer/demonstrate their "normality" to the examiner, often to their disadvantage either through convincing the examiner of their ability or doing themselves damage." - Benefits and Training Officer, Headway Ayrshire

13. From your experience, what impact do awards of PIP have on claimants' ability to stay in, or return, to employment?

For many of our members who claim PIP, work is not an option. Even in this case however, the benefit can support independence and help people play an active role in society.

For those that are able to return to employment, PIP can be the difference between being able to work or not. Schemes such as Motability enable people to reach their workplace, while PIP acts as a passport to many other benefits and support services that promote independence. This is a vital benefit for supporting people with severe disability in the workplace.

14. How does the PIP process compare to similar assessments (e.g. ESA, an occupational health assessment)?

The application process is very similar for both benefits. Each requires the claimant to complete a long and complex form, answering questions that mostly do not relate easily to the effects of a brain injury. Each requires a face-to-face assessment with a non-specialist healthcare professional who, according to our members, often trivialises or ignores the effects of a brain injury.

Claimants do not understand the reasons for having to apply for both benefits separately.

"I have been to several medical assessments with service users and these are usually done by physios/paramedics or nurses who have none or very little knowledge of brain injury. Many of our service users with the 'invisible injury' are declined as the assessment does not cover the cognitive issues that brain injured people struggle with. One physio kept referring to mental health issues when talking about brain injury which we had to correct her on. I feel there should be assessors



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with the relevant experience/medical knowledge of a person's injuries where possible." - Carer Support Service, Headway Bristol

15. In your experience, what are the reasons for people making an appeal to Her Majesty's Courts and Tribunal Service (HMCTS) and what is their experience of this process? Please provide examples. Progress since the last review

The following is a representative experience from the Carer Support Service at Headway Bristol, which supports its members through the appeals process.

"The tribunal itself can be upsetting and distressing. I have witnessed service users having panic attacks and crying etc whilst in the tribunal. Having people sat behind a desk in a very formal way, asking questions over and over again can be intimidating.

"This is difficult for our service users who struggle cognitively and can become confused and very upset with constant questioning. The panel have a job to do but usually only allow the service user to speak and I think other family members/support workers should be able to be more involved.

"Every single tribunal that we have attended has been successful and I am concerned that people who are declined their PIP are not appealing and therefore losing out.

"In fact one of our service users who was originally declined PIP was awarded the higher rate in daily living and mobility recently at a tribunal. He said he at last felt believed as being declined had made him question his injury."

16. Since the first PIP Independent Review, DWP has implemented a number of the suggested recommendations. In your experience, how have these changes altered the experience of people going through the PIP claim process?

We have no response to this question, however it is clear that serious issues remain with the way the PIP application process is delivered. We hope that recommendations from this review will go a long way to addressing this.

17. Do you have any further comments regarding the PIP assessment process?

We have had reports of some of our members having problems attending assessment centres for. Some people are required to travel many miles, and perhaps the DWP could allow home visits as an option on the form?



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We are also extremely concerned about the shortage of proper specialist support for people with brain injury in completing their form, attending the assessment and in some cases going to appeal. While some Headway groups have funding to provide advocacy services, in many cases people are reliant on already over-stretched CAB services, which don't have the deep understanding of this complex condition. This review should lay out a recommendation that the DWP ensures condition-appropriate support is available to all claimants who need it.

On a broader note, it is important to remember that poorly conducted assessments can have a damaging psychological impact on claimants. For people living with an often devastating condition such as brain injury, to feel that their issues are questioned and disbelieved is a huge knock to their confidence, often at a time when this is needed the most. It is absolutely vital that the DWP, Atos and Capita take the feedback from claimants on board and deliver real, measurable, positive changes to this benefit. More claims need to be correct first time, without the need for costly appeal, and assessors need to start with an assumption that the claimant is telling the truth.

About Headway

Headway - the brain injury association is registered with the Charity Commission for England and Wales (Charity no. 1025852) and the Office of the Scottish Regulator (Charity no. SC 039992). Headway is a company limited by guarantee, registered in England no. 2346893.

Brain injury can challenge every aspect of your life – walking, talking, thinking and feeling – and the losses can be severe and permanent. It can mean losing both the life you once lived and the person you once were.

Headway is the UK-wide charity that works to improve life after brain injury. Through its network of more than 125 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.

At Headway, people use insight and care to help survivors regain some quality of life through a wide range of services, including rehabilitation programmes, carer support, social re-integration, community outreach and respite care.

On a national level, Headway provides a range of frontline services to help those affected by brain injury, including:

- a freephone helpline (0808 800 2244, helpline@headway.org.uk);
- a comprehensive award-winning website containing information and factsheets on all aspects of brain injury (www.headway.org.uk);



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- an award-winning range of booklets and publications designed to help people understand and cope with the effects of brain injury;
- 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 network of more than 125 groups and branches that provide physical, cognitive and social rehabilitation and support to individuals and families;
- a directory of approved residential homes, rehabilitation units and respite facilities specialising in ABI.

The charity also lobbies for better support and resources to be made available to people affected by brain injury and works to raise awareness of brain injury and the devastating effects it can have.

