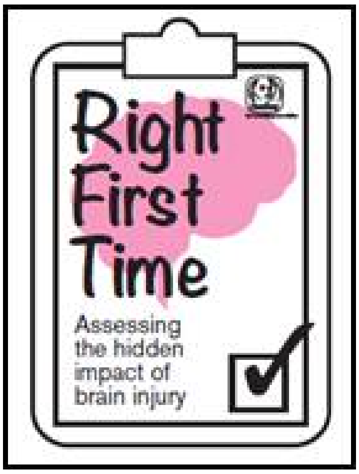
Experiences of Employment and Support Allowance (ESA) and Personal Independence Payment (PIP) after brain injury

Headway
the brain injury association

A study to explore how brain injury survivors feel about the process of applying to the welfare benefits Employment and Support Allowance and Personal Independence Payment.



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Executive summary

The results of the Headway survey *Experiences of Employment and Support Allowance and Personal Independence Payment after brain injury* show that the majority of brain injury survivors have a negative experience of applying for these benefits.

The system of applying for both benefits is reported to be largely focused on the physical impact of having a disability, neglecting other elements of disabilities. For brain injury survivors, the majority of effects that can hinder employment opportunities or affect daily living are 'invisible' and not easily explained on the current application forms. Indeed, 76% and 77% of respondents felt that it was difficult to explain the effects of brain injury on the application form for ESA and PIP, respectively.

Respondents felt that assessors were lacking in specialist knowledge of brain injury. 71% and 60% felt that the assessor for ESA and PIP, respectively, did not have an understanding of brain injury. Further, assessors were widely reported to lack empathy and patience, resulting in a stressful and even traumatic experience for many brain injury survivors. Many respondents also commented on the fact that their medical evidence was not taken into consideration, and that the assessment location/environment was not suitable for them despite requests made in advance.

Consequently, there was a strong sense of frustration and anxiety reported by brain injury survivors and their carers about their needs not being recognised or respected throughout the application process.

Based on these findings, we have made the following recommendations:

- Specialist assessors are needed, who have an expert knowledge of complex conditions such as brain injury. Only 29% of ESA claimants and 40% of PIP claimants felt their assessor understood brain injury.

- Applicants should be offered the option for an audio or visual recording of the face-to-face assessment. They should not have to make special arrangements or provide their own recording equipment for this.

- Third-party evidence such as medical evidence must be actively sought by the assessors and decision makers and taken into consideration in all circumstances

Introduction

In Autumn 2017 Headway conducted a survey to explore the experiences of brain injury survivors when applying for the welfare benefits Employment and Support Allowance (ESA) and Personal Independence Payment (PIP).

ESA is a benefit that can be claimed if someone is unable to work due to an illness or disability.

PIP is a benefit that can be claimed if someone needs support with personal care or mobility for a year or longer due to a disability. It replaces the benefit Disability Living Allowance.

The survey sought to explore how brain injury survivors feel about the processes of application, assessment and, where relevant, appealing a decision.

This report presents a summary of the findings of the survey and their implications.

Background

Research previously conducted by Headway, first in 2012 and subsequently in 2015, on the experiences of brain injury survivors applying for ESA, found that experiences were predominantly negative.

In 2012, it was found that 85% of brain injury survivors felt that the Work Capability Assessment (the assessment for determining eligibility to ESA) did not take brain injury into account, while a further 82% reported that the assessors did not understand brain injury. As a result, many brain injury survivors felt they were not assessed fairly, and were therefore wrongly deemed to be ineligible for ESA.

Alarmingly, when the survey was repeated in 2015, only 7% of brain injury survivors felt the situation had improved over time, and 50% felt there had been a fall in standards. Headway concluded that the WCA was not fit-for-purpose, as it was continuing to fail at identifying people who were in genuine need of welfare support following brain injury.

The same issues are frequently reported by brain injury survivors when applying for PIP. The healthcare professionals carrying out the face-to-face assessment are not brain injury specialists and have only limited training in the condition, so often fail to understand the impact of brain injury. Further, the government has been criticised by Headway in recent years for changing the points-system that PIP assessments are based upon, resulting in claimants receiving much less financial support than they should otherwise be entitled to.

In both benefits, the application forms are long and weighted towards obvious physical disability, making it difficult to explain the invisible but often devastating effects of brain injury.

Recent provisional figures from the Ministry of Justice found that appeal success rates for both ESA and PIP were alarmingly high, at 67% and 68%, respectively[1]. These figures indicate that assessments are not being conducted appropriately the first time around, as they are failing to identify eligible claimants. It is estimated that the cost to the taxpayer in appeals is £40 million alone[2].

Right First Time

Headway's *Right First Time* campaign sets out to challenge the failings of ESA and PIP, by calling for assessors to recognise the impact of brain injury and to ensure that brain injury survivors are treated fairly. The anticipated impact of this reform would be that welfare benefits assessments would be conducted right the first time.

As part of the campaign, a questionnaire entitled *Experiences of Employment and Support Allowance and Personal Independence Payment after brain injury* was hosted on the website Survey Monkey (www.surveymonkey.net). It was promoted via emails to all Headway groups and branches, and on the Headway website and social media channels. Hard copies were also made available to download from the Headway website or sent out on request.

The survey was open from October 2017 to January 2018. It consisted of both closed and open-ended questions to gather quantitative and qualitative responses.

656 brain injury survivors, family members and carers responded to the survey. Headway would like to take this opportunity to thank everyone who took the time to participate.

If you would like to discuss any aspect of the research please contact Tamsin Ahmad on publications@headway.org.uk.

Media requests should be directed to James Coxon on press.manager@headway.org.uk or 0115 947 1901.

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[1] Tribunals and Gender Recognition Statistics Quarterly, July to September 2017, Ministry of Justice
[2] Freedom of Information request made by The Independent and figure reported in August 2017

Key findings

Employment and Support Allowance (ESA)

76%	of applicants to ESA felt that it was difficult to explain the effects of brain injury on the application form.
54%	of applicants to ESA felt that the form was difficult to understand. 51% felt that it was too long.
56%	of applicants to ESA felt that their experience of the Work Capability Assessment had worsened over time. Only 6% of respondents felt it had improved.
69%	of applicants to ESA felt that the assessment did not take brain injury into account.
71%	of applicants to ESA felt that the assessor themselves did not have an understanding of brain injury.
64%	of applicants to ESA felt that it would be a good idea to record assessments, for a range of reasons.
65%	of applicants to ESA who appealed felt the appeals process did not take brain injury into account.

Personal Independence Payment (PIP)

77%	of applicants to PIP felt that it was difficult to explain the effects of their brain injury on the application form.
58%	of applicants to PIP felt that the form was difficult to understand. 57% felt that it was too long.
56%	of applicants to PIP felt that their experience of the face-to-face assessment had worsened over time. Only 13% of respondents felt it had improved.
60%	of applicants to PIP felt that the assessment did not take brain injury into account.
60%	of applicants to PIP felt that the assessor themselves did not have an understanding of brain injury.
59%	of applicants to PIP felt that it would be a good idea to record assessments, for a range of reasons.
69%	of applicants to PIP who appealed felt the appeals process did not take brain injury into account.

Survey results – Experiences of Employment and Support Allowance (ESA) and Personal Independence Payment (PIP) after brain injury

The aim of the survey was to assess what brain injury survivors' and their families/ carers' experiences were during the application, assessment and appeals processes of applying to ESA and PIP. The results of the survey are discussed in this section.

Section one: Demographics

We asked participants whether they were the person claiming the benefit themselves, a close family member or friend, or someone else. We also asked participants their age and how long ago they sustained their injury.

Type of respondent	Responses (%)
The person claiming the benefit	64
A close family member or friend	31
Other	5

Table 1. Type of respondents

Age of respondent	Responses (%)
Under 18	1
19 – 24 years old	3
25 – 34 years old	12
35 – 44 years old	22
45 – 54 years old	33
55 – 64 years old	25
65+ years old	4

Table 2. Age of respondents

How long ago did you sustain your injury?	Responses (%)
0 – 6 months	2
6 – 12 months	6
1 – 2 years	17
2 – 5 years	29
5 – 10 years	18
10 – 20 years	16
20+ years	12

Table 3. Length of time since injury

Section two: Employment and Support Allowance (ESA)

In this section we asked respondents to share their experiences of ESA. This section applied to 72% of all respondents who were in receipt of ESA or had made an application in the last two years.

5% of respondents still had their first claim in progress. 23% of respondents had been claiming ESA for up to a year. The majority of respondents (39%) had been claiming for between 1-4 years. 33% had already been claiming ESA for over 4 years.

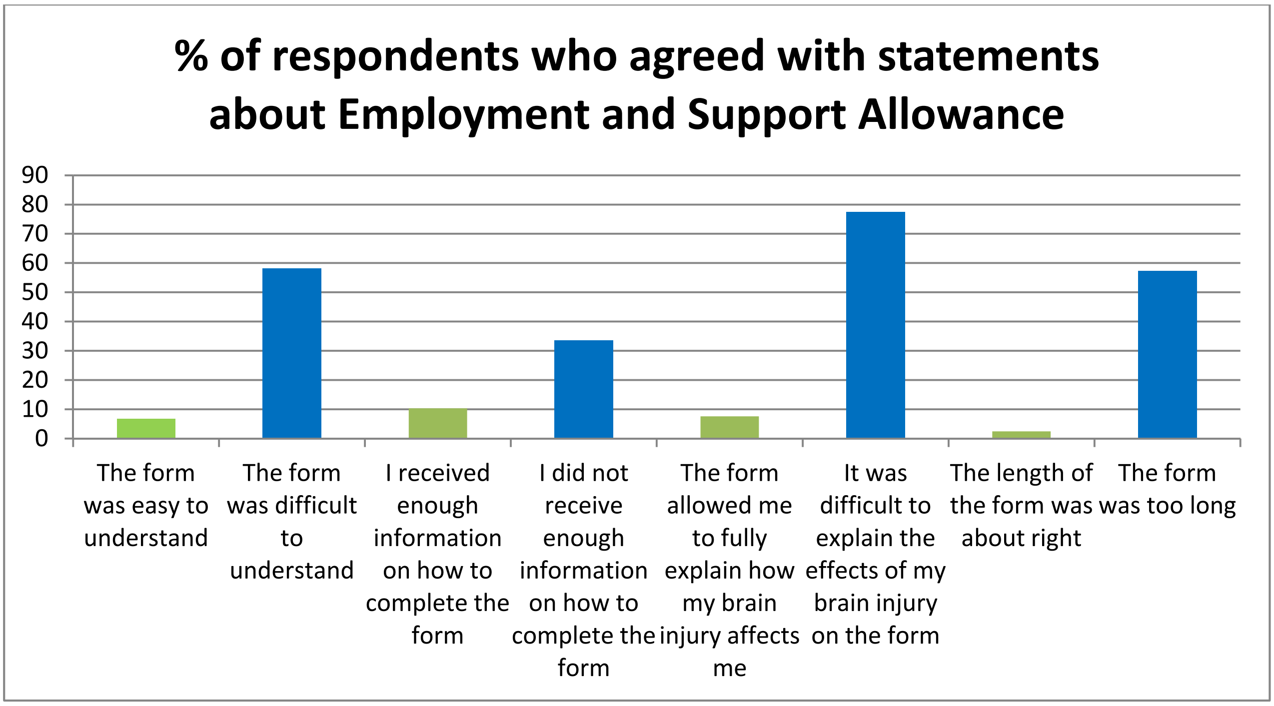
We asked about experiences of the application, assessment and appeals process. These are addressed in turn below.

2.1. Application

We asked participants how they felt about the application form, ESA50. This form comprises the first stage of the ESA application process that offers applicants the opportunity to give information about how their health and circumstances affect their ability to work.

Responses were largely negative. From a list of statements provided, the majority of respondents indicated that they felt the form was difficult to understand (54%) and too long (51%). The most common complaint from respondents was that it was difficult to explain the effects of their brain injury on the form (76%). A third of all respondents (33%) felt that they did not receive enough information on how to fill in the form.

Less than 10% of respondents agreed with each of the positive statements provided in relation to the application, including the form being easy to understand (5%), receiving enough information on how to complete the form (6%), being able to explain brain injury fully on the form (5%) and the length of the form being about right (4%).



We found these complaints to largely be the same when respondents were given the opportunity to share their attitudes towards the application process in their own words. Many respondents commented on the difficulty they had with explaining the impact of brain injury on the form, with the form being seen as "*unfit for purpose*".

> *It was difficult to know where to write about my brain injury as there were no specific questions about it.*
>
> *My disability does not fit a tick box form.*
>
> *The form did not ask me about the impact of my brain injury and how it affects my daily life, which can fluctuate.*

The form was even found to be difficult and frustrating for family members filling it in on behalf of a brain injury survivor.

> *My partner could not adequately fill in the form so I had to. It is extremely difficult to answer for someone else when they cannot answer themselves. I had to use my own knowledge of effects of a brain injury and relate this to how I see my partner deal with life.*
>
> *Very confusing, even for my mum and friends who helped me.*
>
> *I applied on behalf of my wife who, following an assault and TBI, is now in a persistent vegetative state. Filling out the form was fairly ridiculous after spending about 80 minutes on the phone previously, basically stating the exact same things.*
>
> *I found it difficult to emphasise the problems my husband has, because, like everything else in the benefits system, the emphasis is on physical disability.*
>
> *Unable to do at all. Mum tried her best but she has mental health problems and just had another breakdown.*

The process of filling in the form was also deeply upsetting for many brain injury survivors.

> *It was overwhelming and totally frustrating... I cried over it.*
>
> *Absolute nightmare.*
>
> *Having to constantly focus on and repeat the many negative effects of my brain injury (with the pressure of deadline) naturally damaged my mental state.*

Many respondents commented on the fact that it took multiple sittings to complete the form.

> *Took me a week to complete. I did a couple of questions a day with my wife.*

> *It took three weeks to fill in the form, the questions were not specific to the challenges of changes in perception, fatigue, confusion.*
>
> *After completing 3 or 4 pages I had to rest due to fatigue.... It took me a long time to fill in, doing a few pages then having a break, then having to start at page 1 checking what I had done before I could do some more.*

Some respondents directly benefited from the support they received from Headway with the application process.

> *I am very lucky that I have support from Headway. They have helped me so much. If not for them I wouldn't be able to do this.*
>
> *The information given to complete the form didn't really apply to how her brain injury affected her and I found the Headway guide invaluable in helping to explain my daughter's condition.*
>
> *Representative of Headway branch completed the original form.*

2.2. Work-Capability Assessment (WCA)

A number of respondents (27%) had undergone the face-to-face Work Capability Assessment (WCA) more than once. We asked these respondents about how they felt their experience of the WCA had changed over time.

Over half of the respondents (56%) felt that the assessment had worsened over time. This is a 6% increase from our previous study[3], reflecting the unchanged – and indeed, potentially worsening – experience of the WCA.

> *The (previous) assessors were qualified doctors and understood the implications of a head injury. The more recent assessors were not fully qualified and did not know what ABI was. One even admitted to "just need to tick these boxes on the computer."*
>
> *The second time I was assessed the 'Healthcare Professional' did not engage with me but sat behind her computer typing and ticking boxes. I felt I might as well not have been there at all.*

Only 6% of respondents in our current survey found their experience had improved over time, a 1% drop from previously conducted research. Where brain injury was perceived to be understood by the assessor, this made for a more positive and comfortable WCA experience for brain injury survivors.

> *The most recent was carried out with much greater knowledge by assessor and did not make me feel like a fool.*

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[3] Experiences of Employment and Support Allowance and the Work Capability Assessment – study by Headway (2015). For further information, see www.headway.org.uk/news/national-news/wca-improvements-fail-to-impress.

> *The assessor seemed to be more aware of the effects of brain injuries. The questions were more in depth and I could explain in great detail the effects of my brain injury.*

> *The second was with a doctor who understood brain injuries.*

For all respondents who had undergone the WCA, a consistent criticism was that it did not take brain injury into account, with 69% of respondents agreeing with this statement.

> *The assessment only appeared to look at basic physical functions not taking into account the varying and less obvious challenges of a brain injury.*

> *They got it all wrong and don't have any understanding of brain injuries.*

> *No questions about head injury or psychological problems experienced since.*

Only 31% of respondents felt that their brain injury was taken into account during the WCA.

Another core criticism was a lack of understanding about brain injury from the assessors themselves. A startling 71% of respondents felt that the assessor did not understand the effects of brain injury. It is hardly surprising, then, that over half of all respondents (52%) felt that they were not treated fairly in the WCA.

> *Asked various questions, but no real focus on brain injury.*

> *I don't think she understood the various components of memory.*

Some respondents, however, felt that they had understanding assessors, who, despite not necessarily having expert knowledge in brain injury, nevertheless accommodated for the effects of brain injury and appeared to be genuinely empathetic.

> *Mine was very good. You assume they are trying to catch you out but the assessor I had wasn't. I co-operated and felt he listened to me. He would have liked it to have gone quicker and tried to rush me but when he realised that I am slow and genuine he accepted he was going to have a long visit.*

> *I was lucky I saw a doctor who told me he didn't think it was appropriate that I'd had to go for an assessment, he told me not to worry.*

> *The assessment itself was okay as the GP was a very nice man. And he listened.*

> *I feel that the young man who assessed me, listened to me and took time to understand the day-to-day difficulties that I face after having a head injury.*

The WCA was seen as being a ‘tick box exercise’ by many respondents.

> *...After receiving the report it was clear he (the assessor) had just been going through a tick box exercise and not listening to what either of us said.*
>
> *It is done to tick a box.*
>
> *I tried really hard to explain how my brain injury is affecting my life the only time he was recording my answers was when it fit into his very narrow set of criteria.*

Some respondents commented on the lack of consideration given to special requirements needed by them, including travel and input from family members.

> *Would not let parent step in and talk, even though it was written ‘what help will you need in order to attend the assessment?’*
>
> *Ignored family member that attended with me for assistance.*
>
> *On my form I specifically asked for the appointment time not to be during rush hour, as a result of brain injury I now also have hyperacusis and find noise, movement and public transport difficult to navigate... I was given an appointment for 9am and had to find someone to take me.*
>
> *It was in a location with no parking or drop off points nearby. I have difficulty walking.*
>
> *I had to travel... this took over 2 hours on public transport and cost almost £40.*
>
> *My assessment was at 10am in the morning, 45 minutes away from home by car. As myself and my mum got out of car I got a message on my phone saying appointment had been cancelled as I had been double booked. I had been waiting 6 weeks for this assessment.*

Those respondents who were able to have a home assessment remarked that this made for a much easier experience.

> *It seemed friendly and low key. It was carried out in my own home, that made it more relaxing for me.*

Many people felt that the assessment process took too long, or commented on the fact that they were kept waiting for a very long time before the assessment even started.

> *The assessment was far too long at 90 minutes, I was overwhelmed.*
>
> *The assessor took over an hour and tired me out with her intensive questioning.*

> *Waited two and a half hours, wasn't told about the delay, the waiting room was very noisy and lighting was too bright... cried as soon as I went in.*

Another criticism highlighted by respondents was the lack of consideration given to medical evidence that, for some, had taken significant effort to obtain and provide.

> *Did not take any evidence into account whatsoever.*
>
> *Having seen so many experts over the years and amassing a wealth of evidence that I have a brain injury that has a huge effect on my everyday life, but the decision maker simply ignored it!*
>
> *Submitted medical evidence is not properly read. Or not read at all.*
>
> *Not taking any evidence from experts into account.*
>
> *It's hard to get evidence as services are under pressure and don't necessarily have a consultant.*

This issue is of key concern, considering the fact that many assessors lack specialist knowledge about brain injury. Therefore even where this specialist information is being provided, it is not being taken into consideration or used to conduct a fair assessment.

The views shared in this section of the survey highlight a number of major flaws with the assessment process for ESA. The majority of brain injury survivors who responded to this survey failed to be assessed properly, were not offered appropriate opportunities to explain the impact of their injury on their ability to work, and were not treated in a respectful and empathetic manner by the assessor themselves. As a result, many had their application rejected and had to challenge the decision through a tribunal, a stressful and often lengthy undertaking.

We further asked respondents whether they think the assessor should offer to make a recording of the assessment. 64% felt this would be a good idea, with the following reasons given:

> **Evidence in the event of needing to contest a decision**
> *I think if there is proof of what was said/done in the assessments, there'd be less people having to go through mandatory reconsiderations and tribunals to get the money they are entitled to.*
>
> *So that if you have to appeal, you can use it as evidence, and also it would make the assessor carry out a better assessment, hopefully.*
>
> *So there is proof for the claimant when the decision for the claim is declined leaving the claimant with no income, it would help with the appeals process.*

> **As a memory prompt for brain injury survivors with memory problems**
> *With a brain injury, I cannot remember what was said to me or by me, after the assessment.*
>
> *As a result of my SAH I have a poor memory. I thought we had discussed issues in the assessment that aren't referred to on the report. Now I'm not sure if we did discuss it there.*
>
> *Because you could say something and forget what you have just said.*
>
> **Further evidence for the assessment consideration**
> *It might help when attempting to show how difficult it can be to work things out.*
>
> *Because the people who make decisions could see my body language and see how much I was struggling with the interview.*
>
> *So that you can see the amount of time it takes me to answer and the support I require to answer questions*

2.3. Appealing

A number of respondents (25%) had appealed the initial decision of their WCA.

When asked about whether respondents felt their brain injury was taken into account through the appeals process, similar negative attitudes were found. 65% of respondents felt that their brain injury was not taken into account, while only 35% felt that it had been.

Further comments on the appeals process were as follows:

> *Very stressful having to sort out appeal... lots of travelling... not enjoying the whole appeal board... very anxious during it.*
>
> *Long, slow, frustrating... gave me much unneeded anguish. Too complicated when you have a brain injury. Too much jargon. Worked professionally pre-stroke but could not process the initial form or handle the appeal myself.*
>
> *I feel as though I keep filling in the same forms, and as my short term memory is not good I put different information each time. Whenever you call you have to go through the same information again, which I find very upsetting.*

Some respondents, however, had positive experiences of the appeals process. Again, this tended to rely on the genuine empathy of the assessor.

> *The assessor who undertook the mandatory reconsideration was very understanding and I felt open to looking at additional evidence, for example I referred her to the Headway website which she referenced in her report. She was very helpful, however.*

> *The eventual tribunal hearing was conducted in a mature and sensible manner. The judge and medical professional were patient and empathetic. They appeared to see how difficult this had all been for my son and how ridiculous the whole process had been over eight months.*
>
> *Thank god there was a judge and doctor who showed me an immense amount of respect and care. They even felt they had to apologise for the way I had been treated.*

Section three: Personal Independence Payment (PIP)

In this section we asked respondents to share their experiences of Personal Independence Payment (PIP). This section applied to 70% of all respondents (who were in receipt of PIP or had made an application within the past two years).

15% of respondents still had their first claim in progress. 24% of respondents had been claiming ESA for up to a year. 51% had been claiming for between 1-4 years. 6% had been claiming for over 4 years, and 4% were unsure of how long they had been claiming for.

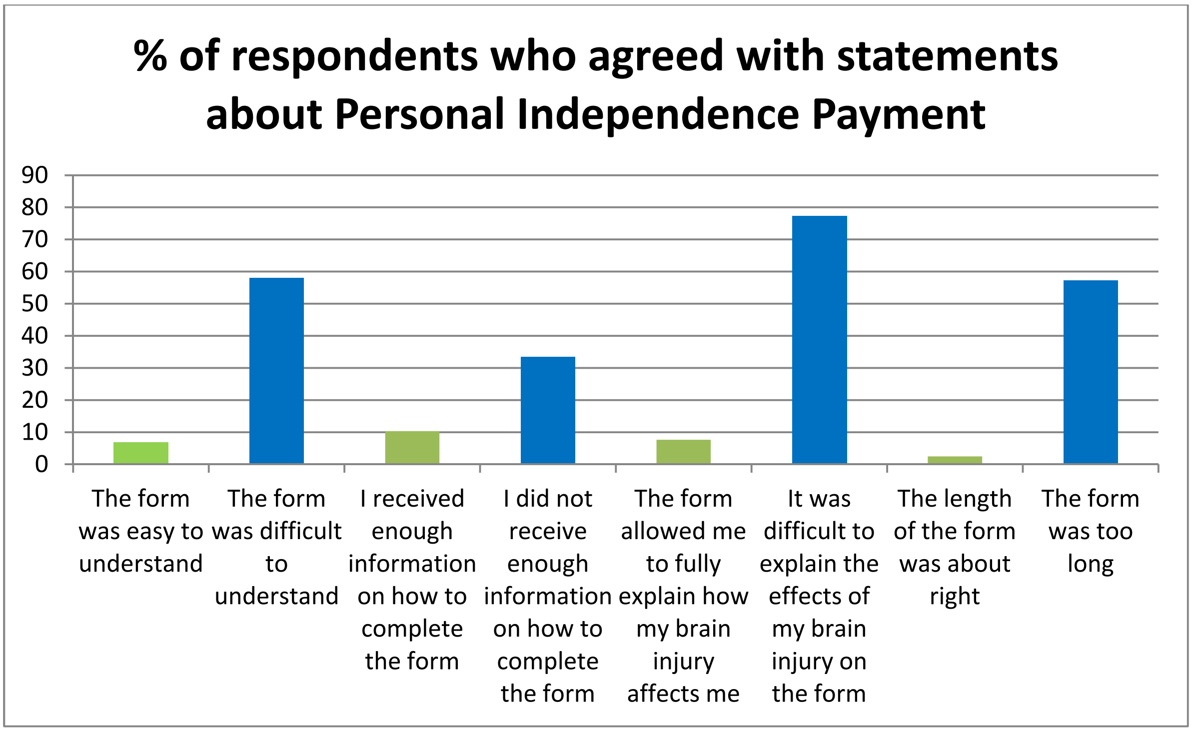
We asked about experiences of the application, assessment and appeals process. These areas are addressed in turn below.

3.1. Application

We asked participants how they felt about the application form *How your disability affects you*. This form comprises the first stage of the PIP application process that offers applicants the opportunity to give information about how their health and circumstances affect their day-to-day living.

When asked about experiences of filling in the form, responses were largely negative. From a list of statements provided, the majority of respondents indicated that they felt the form was difficult to understand (58%) and too long (57%). The most common complaint from respondents was that it was difficult to explain the effects of their brain injury on the form (77%). Just over a third of all respondents (34%) felt that they did not receive enough information on how to fill out the form.

Only 10% of respondents felt that they received enough information to fill out the form. Less than 10% of respondents agreed with each of the remaining positive statements, including the form being easy to understand (7%), being able to explain the impact of brain injury fully on the form (8%) and the length of the form being about right (2%).



We found these complaints to largely be the same when respondents were given the opportunity to share their attitudes towards the application process in their own words. Many respondents commented on the difficulty they had with explaining the impact of brain injury on the form.

> *There were not enough opportunities to fully explain how much brain injury affects me.*
>
> *The questions asked don't cover brain injury issues... the PIP form seems more aimed at physically disabled rather than those with mental health or brain injury.*
>
> *The form is very broad and only looks at certain things, there is nowhere to put how something affects you differently. For instance, I cannot filter noise and am partially deaf, it takes into consideration the deafness but there is not anywhere to put information about other hearing difficulties.*

Many respondents depended on family and friends to help them with filling in the form, or completing the form entirely on their behalf.

> *For me the completion of any form is extremely difficult, if not impossible without considerable help.*
>
> *Had to be completed by family member.*
>
> *The form was impossible for me to understand on my own because I am unable to read as a result of my brain injury. With my father reading,*

> *interpreting and filling in the form I was able to fully explain how my brain injury affects me.*
>
> *Had to be done by parent. Would not have been able to complete by claimant.*

Some respondents commented on the professional support they required.

> *The Headway support worker helped us well.*
>
> *Got lots of help to fill in long form. From disability officer from Citizen's Advice.*

The length and format of the form were also considered to be cumbersome.

> *I could not believe how long the form was, it was totally unsuitable for a brain injury survivor to attempt to complete on their own (and not all survivors have family around to help).*
>
> *It took hours to complete the form. I was completing it on behalf of the person I care for and spent ages looking at government and charity websites to get help on what to write.*
>
> *Fields too small, LOTS of additional sheets submitted.*

3.2. Face-to-face assessment

Only 23% of respondents had undergone the face-to-face assessment more than once. However, as PIP was only introduced in April 2013 this is not surprising. We asked these respondents about their experiences across each assessment they had undergone.

Over half of these respondents (56%) felt that the assessment had worsened over time.

> *First review was at home with an ex-paramedic as the assessor. The second was in an office with an assessor who seemed more of an administrator than healthcare professional.*
>
> *My first assessment was at home, whilst it was a difficult process I was given time to answer and I felt like I could give a pretty clear picture of how my stroke affects my life. In my review assessment I felt it was rushed, I was asked very closed questions, interrupted several times, I don't feel that my specific needs were taken into account and I don't feel I was able to give a very clear picture of my daily difficulties or the extent I am affected.*
>
> *This time I had to go into an office. But first time a man came to my home which I preferred.*

> *My first assessment was great, the assessor understood brain injury and had worked on brain injury and stroke units. She was kind and listened. The second assessment was dreadful.*
>
> *My first face-to-face was good and the lady understood me. The second was awful and I was made to feel like I was lying.*

12% of respondents found their experience had improved over time. Where brain injury was perceived to be understood by the assessor and home assessments were offered, this made for a more positive and comfortable assessment experience for brain injury survivors.

> *My second assessment took place as a home visit instead of a round trip of over 100 miles.*
>
> *The interviewer was more compassionate.*
>
> *The woman was more interested in my TBI and showed more concern.*

For all respondents who had undergone the face-to-face assessment, 60% agreed that it did not take brain injury into account.

> *I was asked various questions but it was mainly based on my medical history and not so much about how my condition affects me on a day-to-day basis. I don't feel this element was explored enough.*
>
> *It was more focused on what you can do physically in and around the home... no questions about your mental state, abilities or difficulties due to brain injury.*
>
> *The person who conducted the assessment did not seem to understand how brain injuries affect people how they are "invisible" or what their impact is...*
>
> *The assessor had no specialist training on the multiple complexities of brain injuries.*
>
> *The PIP assessment did not account for brain injury at all; they are basic questions that are completely unsympathetic to those with brain injury.*

Respondents largely felt that the assessors did not have an understanding about brain injury. 60% of respondents explicitly agreed with this statement.

> *I felt like I was making it all up because I was given an idea of what they should have asked and they did not ask about my brain injury at all.*
>
> *The assessor... was pleasant in her manner. However, she did not appear to have specialist knowledge of TBIs. She had not heard of Headway so we had to explain this. The focus was very much on the 12 daily activities and there*

> *was very little time or opportunity to mention the less visible effects of my partner’s TBI.*
>
> *Medical examiner was a nurse who had no idea of how brain injury affects people.*

Of those who did report a more positive experience of the face-to-face assessment, this was attributed to having an assessor with an understanding of brain injury, patience and empathy.

> *The lady was patient. Listened and didn’t try misleading me.*
>
> *Seen by a nurse who seemed to be more aware of brain injury and questions more geared to our issues and health after the injury.*
>
> *It was done at home which helped but I’m worried about the next one because I have good and bad days.*
>
> *The assessor was very nice, friendly and seemed to really listen to me.*
>
> *It was clear to me that the person conducting the assessment had a good knowledge of brain injury... and he understood how the nature of these could impact on everyday life. I felt confident throughout the assessment that my husband was being viewed as an individual and his needs were being assessed fairly.*
>
> *The lady was helpful, kind and considerate.*

Where respondents had to travel to an assessment, many felt that this caused undue stress that worsened the entire experience. Further, some survivors reported negative conditions of the assessment environment.

> *I found it very difficult to get to the appointment and unbelievably stressful which is something I suffer with and am told to avoid at all costs.*
>
> *I had to attend a private physio premises on a busy high street, and it was difficult to find parking nearby.*
>
> *Had to be taken miles from home to a strange place, waited for hours on hard chairs, was stressful, painful and degrading.*
>
> *Sitting in the waiting room was like a torture chamber, it was far too loud... and they could not facilitate my needs of needing a quiet area, leaving me in pain for 50 minutes.*

Having the opportunity to have a home assessment made a significant difference to people’s attitudes towards it.

> *A lady with a physiotherapist background came to my home. I had my wife and Headway worker with me... It was better at home.*
>
> *Went very well. Assessor came to my home and was very helpful. Understood brain injury and effects.*
>
> *Home visit. Was more settled and relaxed. Didn't feel under pressure.*
>
> *Carried out at home which helped and a lot of help and support from a friend, the assessor was very supportive.*
>
> *Home visit. Very sympathetic and understanding. Listened to everyone's input.*

Some respondents commented on the fact that others' input was not taken into consideration.

> *The interviewer was not interested in any comments from my family member who attended with me. All questions were directed at me even though I had a letter from my doctor stating that I could not be relied upon to answer questions accurately... I felt that the face-to-face interview was very official and extremely cold, and did not give my family member a chance to explain fully the extent of my injury and the effect it has on my daily life.*
>
> *The assessor would not let my helper talk, just pushed me for answers.*
>
> *Partner was not allowed to speak.*

Even medical and professional evidence was reported to not be taken into consideration.

> *The health professional ignored evidence from more qualified health worker such as consultant neurologist... ignored diagnosis from consultant.*
>
> *She has... negated what one of the top neurologists in the UK has said about me and my brain injury.*
>
> *The assessor asked my client if he can make a cup of tea. He said yes, which she took as the answer. As his Occupational Therapist tried to interject, she told me to 'please be quiet'. She would not chat with me or take into consideration my opinion as the highly specialist therapist in brain injury.*
>
> *She didn't listen to me, ignored my GP records where it explained my mental health and brain injuries.*

Inaccuracies in the final assessment report were also seen to be major problems.

> *The eventual report had so many errors, claiming that my son had said/done things in the interview that did not happen (he wasn't capable at that time of doing the things that were stated!)*
>
> *The report was not a true record of the interview!*
>
> *Assessor seemed nice seemed to understand at the time however the report was not an accurate reflection of what was said at the assessment and clearly the assessor did not understand some of what she was told.*
>
> *I do not think the assessment was an accurate reflection of my husband's condition. I do not think the assessor's written responses were an accurate reflection of the assessment.*
>
> *None of my answers tallied with their report.*

The views shared in this section of the survey highlight a number of flaws with the assessment process for PIP. The majority of brain injury survivors who responded to this survey failed to be assessed properly, were not offered appropriate opportunities to explain the impact of their injury on their day-to-day living, and were not treated in a respectful and empathetic manner by the assessor themselves. Medical evidence was often not taken into consideration. As a result, many had their application rejected, and had to challenge the decision through a tribunal, a stressful and often lengthy undertaking.

We further asked respondents whether they think the assessor should offer to make a recording of the assessment. 59% felt this would be a good idea (32% were unsure), with the following reasons given:

> **Evidence in the event of needing to contest a decision**.
> *So it gives a fair, unbiased account of the assessment, which can be referred to!*
>
> *An audio or visual recording would provide the hard evidence when appealing against a decision that the exact phrase was said and then interpreted.*
>
> *This makes sure everything you say is recorded and no false information can be put down on paper or missed out.*
>
> **As a memory prompt for brain injury survivors with memory problems.**
> *It would have proved helpful later as I have memory issues and could not recall certain aspects of the assessment.*
>
> *It would prove what support I had on the day, it would help me remember what happened.*
>
> *Significant memory problems mean a recording that can be referred to later would have been very helpful.*

> **Further evidence for the assessment consideration.**
> *You can look normal, but language and behaviour are affected, as is memory and word finding abilities. This is only evidence on video, not a written report.*
>
> *I wasn't asked about how I felt about the physical movement I had to do, but it would have been obvious on video that I was in pain.*
>
> *Simply because there is a lot of 'interpretation' often wrongly.*
>
> *Doubts can be confirmed and others can give an opinion on the assessment.*

3.3. Appealing

A number of respondents (34%) had appealed the initial decision of their face-to-face assessment.

When asked about whether respondents felt their brain injury was taken into account through the appeals process, similar negative attitudes were largely reported. 69% of respondents felt that their brain injury was not taken into account, while only 31% felt that it had been.

> *The hearing was conducted in a condescending manner throughout, by the judge and the two attending professionals. They admitted that ABI was not within their expertise.*
>
> *Not taking on board full impact of brain injuries and how they affect our life.*
>
> *Clearly did not take into account my medical conditions or needs.*
>
> *Classic example of "not all disabilities look like this"; just because I don't have a stick or a wheelchair does not mean I am not struggling.*

For many, the appeals process was incredibly stressful.

> *Apart from it costing me quite a bit of money for photocopying and postage costs, I felt I was jumping through hoops to get what I believe I was fully entitled to. I was also told that the onus is on the claimant.*
>
> *The support from Citizen's Advice was very good on paper but no representative was available to attend the hearing. As my son's appointee I was the only person available to attend and I felt out of my depth.*

Many respondents also commented on the length of time it took to be seen.

> *The time factor is one issue. I applied in March, was assessed in either June or July... sent my request for mandatory reconsideration... now approaching the end of October, I'm still in the limbo state of awaiting a tribunal date... If the system wasn't so fundamentally flawed, the right decision would be made the first time.*

> *Attending appeal in 5 weeks after waiting 9 months for a court date.*
>
> *It's taken months to get to tribunal, now still waiting to attend.*
>
> *The case has been with the appeal court for the last 8 months!*

Overall findings

The survey *Experiences of Employment and Support Allowance and Personal Independence Payment after brain injury* sought to explore how brain injury survivors feel about the welfare benefits assessment processes for ESA and PIP.

The overwhelming majority of respondents felt that their experiences were negative, for a variety of reasons.

The reasons given were:

- application forms did not have adequate space to explain the impact of brain injury
- assessors did not have a good understanding of brain injury
- assessors were not empathetic
- assessments were held at a location that was difficult for the brain injury survivor to access
- assessments were not recorded
- medical evidence was not taken into consideration
- family members' input was not valued or taken into consideration
- appeals process did not take brain injury into consideration

These findings, although troubling, are not new. Numerous reports have identified such problems in the benefits system, with research being conducted as recently as 2017 that identified the challenges faced by brain injury survivors applying for ESA (Potts, 2017; Mueller et al, 2017). Organisations such as Headway and the British Psychological Society have consistently called for these issues to be addressed.

Although some respondents reported having positive experiences, it remains clear that there is a consistent emphasis on physical disabilities, overlooking and thus failing to support those individuals with a 'hidden disability'. Indeed, many brain injury survivors with a range of psychological, cognitive and emotional effects have a legitimate claim to the welfare benefits ESA and PIP, yet their needs are not being recognised, respected or treated accordingly. As a result, many find themselves being pushed towards undertaking the long, arduous and stressful process of appealing. This process has been found to cost millions of pounds to the taxpayer, millions of pounds that could be saved if assessments were conducted right the first time around.

Closing comments from respondents on the welfare benefits system only reiterated the aforementioned issues.

> *It doesn't work, it's broken with assessors who have no proper training, a complicated lengthy process that actually I believe has already made its decision before you send your form.*
>
> *I think it is very unfair that people with hidden disabilities are treated so poorly.*
>
> *The people interviewing should at least have a sufficient insight and knowledge of the medical problems that the person they are interviewing is faced with daily.*
>
> *I am an educated person who is 55 years old. I have never had to claim benefits up until my son's accident. PIP and ESA is so difficult and stressful to do whilst supporting and living with someone with a brain injury. It caused me to want to give up. The process was lengthy and seemed like a barrier to benefits. It felt like it has been made difficult to put people off from applying.*
>
> *The whole system needs to be simplified and DWP/Capita/Atos staff trained to understand what it is to be disabled... A solution may be for those involved in the implementation of PIP/ESA is to spend a significant length of time working with the disabled to see what we are talking about.*

Recommendations

The results from this survey yielded a number of recurring issues across application processes for both ESA and PIP that demonstrated a flawed assessment process for a number of reasons. Based upon the responses yielded from over 500 individuals, some of whom were professionals themselves, Headway makes the following recommendations:

ESA and PIP application forms

- The forms were perceived as being too long and did not specifically ask applicants about the cognitive impact of disability. The forms should be shorter and amended to specifically ask about cognitive impact of disability.
- The forms were difficult for many to fill in due to the lack of guidance notes specific to their condition. There should be clear, relevant guidance notes available with every application form to make this simpler for applicants to fill in.

ESA and PIP assessments

- Family members and advocates were not routinely invited to offer input at assessments, despite some brain injury survivors lacking insight of the impact of their injury or forgetting key points due to memory problems. Input from

family, and advocates, and medical evidence provided by GPs and other healthcare professionals, should always be actively sought and taken into consideration.
- Assessors were found to lack specialist knowledge on brain injury and its impact, therefore lacked the necessary skills to conduct an appropriate assessment for a brain injury survivor. All assessors for brain injury survivors should have this specialist knowledge to ensure a fair and appropriate assessment.
- Assessments were not offered at convenient locations. Individual accommodations for assessments should be made when required by the applicant. Home assessments should be in a timely manner to all claimants who report difficulty reaching the assessment centre.
- The option of having an assessment recorded was considered to be a good idea by many respondents for a number of reasons, but there are currently significant barriers to doing so. Applicants should therefore be supported in recording their assessment.

Conclusions

This report summarised the findings of the Headway survey *Experiences of Employment and Support Allowance and Personal Independence Payment after brain injury.* The collective response from over 500 individuals highlighted a number of problems with the process of applying for these benefits after a brain injury, largely due to the lack of recognition and understanding of brain injury among welfare benefits assessors. Headway has made a number of recommendations that, if implemented, would reduce the number of brain injury survivors experiencing stressful application processes and needing to appeal benefits decisions, by getting the assessment right the first time.

Acknowledgements

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