Fifth Independent Review of the Work Capability Assessment

Headway – the brain injury association response to the call for evidence

August 2014

Introduction

Headway welcomes the opportunity to contribute to the fifth independent review of the Work Capability Assessment (WCA).

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 Employment and Support Allowance (ESA) through our network of groups and branches and other frontline services such as our national helpline.

To inform our response to this, the fifth and final independent review of the WCA, we are including early results of a survey of our members that asks for their views on the assessment and how it has changed over time. This survey mirrors a similar study we ran in 2011/12, and a comparison allows us see whether previous independent reviews have led to positive changes in the experiences of people with a brain injury.

Question responses

This section includes our responses to the questions for people responding on behalf of a charity.

The impact of previous independent reviews

Q) Over the course of the last four independent reviews, a number of recommendations have been made and implemented. How have these changes altered the experience of people going through the WCA? Please provide supporting evidence.

We are seeing very little evidence from our service users that the annual changes over the last five years have had a positive impact on the WCA.

In our most recent survey, 53% of respondents who have had multiple WCAs felt that the assessment had ‘worsened a lot’. 42% felt it had ‘stayed the same’, with only 5% feeling it had ‘improved a little’. Nobody felt that the WCA had improved significantly.

Comparing the interim results of our most recent survey with those of our 2011/12 study:

	2011	2014
Do you feel the assessor understood the effects of brain injury?	Yes: 13% No: 87%	Yes: 8% No: 92%
Do you feel the WCA took account of your brain injury?	Yes, completely: 4% Yes, a little: 11% Not really: 30% Not at all: 54%	Yes, completely: 5% Yes, a little: 13% Not really: 33% Not at all: 49%
Do you feel you were treated fairly in the WCA?	Yes: 20% No: 80%	Yes: 21% No:79%
Did your application for ESA take evidence from third parties into account?	Yes: 40% No: 60%	Yes: 43% No: 57%

These results provide a stark picture of the Work Capability Assessment which, despite four years of independent reviews, has failed to improve to an acceptable level.

People with brain injury are still being let down by an assessment that takes little account of the complexity of their condition, and leaves them with a feeling of being misunderstood.

Given these results, it is still hugely concerning that this is the final year in which an independent review will be conducted on the WCA. It is vital that this evolving and still relatively new benefit is subject to continued independent scrutiny to ensure it meets its objectives.

Experiencing the WCA process

Q) In the fourth Independent Review Dr Litchfield recommended that the ESA50 and all letters and forms should be reviewed to improve how the DWP communicates with people undergoing a WCA. Are there any other specific areas for improvement in the way that the WCA communicates with people? Please give details of specific areas for improvement.

The DWP offers no additional support for those who experience short-term memory, attention and concentration problems. Our members report severe difficulties on receipt of an application form and accompanying letter.

Many claimants forget that they have received the form, lack capacity to complete it and have no guidance on where to find appropriate support. Many will miss application deadlines and be removed from the ESA claim process. Far from being a sign that they have dropped out of the claims process due to ineligibility for the benefit, it is an indication that the benefit is inaccessible to a group of people who need it the most.

Additional support should be provided to people with brain injury, starting with an initial needs assessment – conducted by a professional with a working knowledge of brain injury – followed by services to help them complete the form. Emphasis should be placed on the importance of completing the form in a timely manner, and the claimants should be signposted to appropriate local support services.

Brain injury is a complex condition that fluctuates from day-to-day, and in many cases hour-to-hour. Fatigue is an important contributor to this, and is one of the most common and debilitating effects of a brain injury. Because of this fluctuation, many people will tick the 'It varies' box on the ESA50 form, indicating the fact that on *some* occasions they may be able to complete a task, however in reality due to changes in their condition throughout the day they will not be able to do this reliably.

The 'It varies' box is a misleading option for people with brain injury who are unaware of the 'reliably' criteria for all ESA descriptors. We have anecdotal evidence that indicates people who tick this box are treated as having no problems in the related area, and as such it appears to operate more as a trap to deny people the benefit they need rather than providing a full account of disability.

We would ask that decision makers and assessors are advised to use discretion when a claimant with brain injury answers 'It varies'. Guidance should be issued to make it clear that, with further investigation, this answer may often indicate that the activity cannot be completed reliably. The full reasons behind their answer should be investigated as part of the wider assessment before any firm decisions are made as to their score for a particular descriptor.

The DWP should also work to inform claimants about the 'reliably' criteria that must apply to all descriptors, so if a person cannot complete a particular activity reliably, repeatedly, in a timely manner or safely, they can answer accordingly. This principal is vitally important, and correct application in the WCA process could greatly reduce the number of incorrect decisions.

Q) At certain points in the WCA process, either a person must take action to progress their claim or the expectations placed on them change. For example: action is needed if the person wants a mandatory reconsideration; and expectations change when a person is placed in the Work-Related Activity Group (WRAG) and is expected to undertake work-related activity.

Is the information currently provided to explain the process or the expectations of the person undergoing a WCA adequate? If not, please consider what further information would be useful and why, and who would benefit from it, and provide supporting evidence.

Communication of the process for appeal, and the need for a mandatory reconsideration, is inadequate. This needs to be made clear much earlier in the WCA process, so people have a clear idea what they must do if they disagree with a decision. Again, local information should be provided on where a claimant can obtain support.

If the claimant is accompanied to the WCA then the person providing support should also be notified of the outcome. This will provide an opportunity for the supporting person to make adequate preparations for the mandatory reconsideration and any subsequent appeal, taking some of the responsibility away from a potentially highly vulnerable claimant.

Training should be given to DWP decision makers as well as WCA assessors to ensure they are able to identify people who have higher support needs, and provide adequate help as required.

Many claimants are similarly unaware of the responsibilities placed on them in the WRAG and feedback from our survey highlighted the inappropriate support offers to these claimants. See the WRAG question below for more details.

Q) In October 2013, ‘mandatory reconsideration’ was introduced for a number of welfare benefits. Concentrating on the mandatory reconsideration process for WCA decisions, how do you feel this process is working? Please detail areas that do or don’t work well, and provide supporting evidence.

There is a perception that the mandatory reconsideration phase simply supports the original decision, however we recognise that the attempt to resolve disputes without the need for a lengthy tribunal could be in the best interests of claimants in many cases.

We have concerns about the lack of a time limit for a mandatory reconsideration; with no firm guidance on the time it should take to reach a conclusion there is additional uncertainty placed on some of the most severely disabled claimants.

We are also seriously concerned that claimants cannot receive any payment while waiting for the reconsideration from the DWP. 'Assessment rate' of ESA is only available once a formal appeal has been lodged, leaving many people who are later awarded ESA without income, or on JSA with its unsuitable requirements. This situation can also have a knock-on effect on other income, such as Housing Benefit and Council Tax Reduction. We urge this review to recommend assessment rate be paid from receipt of a request for reconsideration.

We note that detailed statistics on how the mandatory appeals process is working are intended "for future publication" and as such freedom of information requests asking for them are currently being denied. We ask that these statistics be released as quickly as possible, to allow a reliable investigation into how the process is working.

Q) Thinking about the overall WCA process from when someone makes a claim to when they receive the final decision notification from DWP, are there areas where the WCA doesn't work well and/or could be improved? If so, please give details of the improvements you would make, and provide supporting evidence.

The initial claim process should be examined for people with severe cognitive disabilities. The time from receiving the ESA50 form to requiring its submission is unreasonably short and, particularly without guidance towards appropriate support, can be an insurmountable problem for many claimants with brain injury.

Benefits support services such as those provided by Citizens Advice Bureau and more brain injury-focused support provided by Headway are extremely stretched and long waits can be encountered even after a claimant has been referred to the service.

The WCA could be improved if claimants and/or their representatives were contacted by DWP staff immediately after the initial application where cognitive disability is indicated, to set suitable deadlines for the individual claimant. This could flag up the need for additional support during the claim process, and lead to follow-up from DWP staff if a claimant does not meet a deadline instead of withdrawal from the WCA process.

There is also feedback that suggests frequent delays in receiving copies of WCA paperwork for claimants who are appealing. The DWP should send all necessary paperwork in a timely manner, to allow claimants and their representatives to make adequate preparation for appeal.

Again the timescales for appeal give no recognition of an individual's ability or personal situation, and DWP staff should be making contact with them to agree appropriate and realistic time limits.

Predictably, most respondents to our survey were able to provide examples of times when the WCA does not work well.

Selected comments include:

"Repeatedly telling your story to different people. Keeping folk waiting around on the day you go for your WCA . The way you are treated in the offices as you wait. Assessors not taking other account of other written evidence. Seems like it's probably an expensive way to get the job done."

"It didn't take into account my husband's speech and language problems. The assessor was clearly only looking for physical and mental reasons not to work. The report came back with inaccuracies."

"Unfortunately the nature of brain injury means that behaviour can vary day to day. A 10 minute interview with multiple ticking of boxes does not adequately evaluate the person being assessed. I believe that an education process to support the staff to

understand how it is impossible to assess fatigue or cognitive functions in a 10 minute session!"

"Does not take into account any previous reports and assessments. It takes too long to find out the results. The questions are fixed, for someone with a TBI not easy to understand it is an unseen disability so it is assumed they are capable of working. There is no opportunity to say what things are a problem, i.e. fatigue, short-term memory. [Name removed] is not capable of filling out a form, first he can't write much and second he wouldn't understand the written questions - if I didn't do this I doubt he would get ESA."

"The form application process is not appropriate for head injury/psychological problems, as is the assessment. A snapshot in time does not represent the enormous variability of conditions' symptoms, and an assessment shows you this failure to assess the range of severe problems that I face."

"I found the process demoralising and I became more depressed, almost losing the will to continue to live. It is incredibly difficult for me to explain my problems and condition, especially to someone who is not experienced in this speciality - the assessment is made by unskilled inexperienced staff who do not comprehend. As I have severe cognitive impairments, someone like a neuropsychologist who knows me should make the assessed application on my behalf and consult with any assessor. I have memory impairments, communication problems and don't organise myself or thoughts well, so being interviewed live cannot retrieve all pertinent information - for this reason alone, the assessment is biased against me and should not be undertaken. Someone like myself should have a waiver from assessment, and only medical information being supplied should be sufficient to do this."

Q) Are there areas where the WCA process works well? How could these be built on to improve the experience of people going through the process? Please explain the impact that you would anticipate this having, and provide supporting evidence.

When asked this question, many respondents to our survey were unable to provide positive experiences of the WCA. However there were constructive comments, including:

"I believe that the opportunity exists to provide support for those with brain injury - either in understanding that often returning to work is not possible....or providing the best support to help those that can work return to work. It would be extremely beneficial if the ESA and WCA worked with local Headway branches to help understand brain injury (and use support services to help get those back to work that can work)"

"Re the ESA, I was put straight in the Support Group, WITHOUT needing to Assessed!! Perhaps, it was because I appealed against my DLA ruling & I was awarded the Higher Rate, Indefinitely!!!!"

Most claimants understand that the assessment is a necessary process, but have an issue with the way it is implemented.

With this review and the upcoming change in delivery contract for the WCA, the DWP has an opportunity to make lasting, positive changes to the assessment process. Working with and funding support organisations to help claimants with severe cognitive disability to navigate the process would be extremely beneficial, and Headway would welcome discussion on this.

It is positive from our survey that some claimants are being awarded the benefit without the need for a face-to-face assessment, however they still need to navigate the difficult ESA50 to reach this point. This review could recommend that more claimants, especially those who have relevant awards of other benefits, are moved on to ESA without the stress of additional assessment.

One member said:

"I cannot think of anything, although I can understand the need for it. I think that brain injury is too complex to be looked at so simplistically. Personally I could get myself to a workplace but would be so exhausted I doubt I would be fit to work at all, never mind the concentration etc needed, then of course I would have to get home!"

The assessment needs to be adjusted to take a reasonable look at a full day at work, rather than a series of tasks taken in isolation. When fatigue is an issue as it is with brain injury, an assessment in the format of the current WCA can never be a reliable measure of a person's ability to work.

The WRAG and Support Group

Q) In Employment and Support Allowance there are two groups that people can be placed in following the WCA process; the WRAG or the Support Group. Do you feel that the WCA is generally effective in correctly placing people in either the WRAG or the Support Group? If not, please detail areas of difficulty and provide supporting evidence.

It is clear that, at least in our client group, many people are being placed in the WRAG incorrectly following the WCA. This is causing undue pressure and confusion for claimants, as well as unreasonable expectations on JobCentre Plus staff who are unable to provide appropriate work-focused support to claimants.

The results of our 2014 survey show that:

- 53% of respondents who are currently in the WRAG feel that they should have been placed in the support group.
- 27% feel that the WRAG does not help them get back into work

- 60% feel the support received is not suited to people with a brain injury
- 20% feel that the requirements placed on them are unreasonable

Comments from the study tell a story of people inappropriately placed in this group, and the frustration of DWP staff who are ill-equipped to help them:

"They keep trying to get me volunteer in care homes but I keep telling them I have behaviour problems which a neuropsychiatrist has said on a report"

"It was a short lived experience and raised multiple anxieties. I explained that we were appealing and that we would keep pushing back appointments. Thankfully the person in the work related group agreed with my assessment and was helpful in the appeal process."

"My husband was placed in this group 2 years ago. We attended meetings but the job centre couldn't offer us any support. There were no groups my husband could attend other than his speech and language therapy which he was already doing."

"I am now due to balance and other side effects of op unemployable from both an insurance and health and safety point, the DWP seem to be the ONLY people who don't accept this!!"

"My partner sees an adviser at the job centre every 6 months. His assigned advisor is very patient with him. It’s the system that is harsh."

JobCentre Plus staff who identify claimants who they feel have been incorrectly placed in the WRAG should be able to trigger a review of the claim, with a view to moving them into the more appropriate Support Group.

Mental Health and Learning Difficulties

Q) The WCA aims to differentiate between moderate or severe impairment of a person’s capability for work, resulting from a health condition or disability. For those with severe and enduring Mental Health conditions or severe Learning Difficulties:

a. what examples can you provide of this differentiation not working well? Please detail the parts of the WCA that contribute to this and provide supporting evidence.

Acquired brain injury is not a mental health condition, it is a distinct condition in its own right with a unique combination of cognitive, emotional, behavioural and physical effects that lead to particularly complex disability. However, for the purpose of many DWP activities such as ESA, the WCA and reviews such as this one, brain injury is often included under the ‘mental health’ banner. We would appreciate a move towards more inclusive language that recognises the complex nature of this condition, while giving it special consideration as with mental health conditions and learning disability.

For the purpose of this document we will provide feedback to this question based on the experiences of people with acquired brain injury.

As detailed above, it is clear that many claimants are being placed incorrectly in the WRAG when the Support Group would have been more appropriate. Our survey results demonstrate the failure of the WCA in differentiating between moderate and severe disability and placing claimants accordingly.

The ESA50 form could be adjusted to give more space to report the effects of cognitive dysfunction. Headway would be pleased to offer support to the DWP in doing this.

At present the form puts emphasis on physical functions, with limited opportunity to describe how the cognitive, emotional and behavioural effects of a brain injury affect the claimant. Part 2 of the form does offer this, but given the limited number of scenarios considered it often takes specialist support workers to explain how to record the effects of a brain injury in here.

Guidance notes or the form itself should at least provide information on equivalent tasks to assist people whose disability may make it hard for them to work this out. For instance, question 11 uses setting an alarm clock as an example of a simple task. It would be helpful to mention alternative tasks such as turning on a TV and using basic functions of a remote control, rather than simple stating ‘or equivalent’.

Furthermore, our members often lack insight into how their condition affects them or have an unduly positive opinion of their abilities, and this can have a detrimental effect on their scoring in the WCA.

The key indicator of the WCA, "whether a person would pose danger to themselves or the workplace if they were placed into employment", again focuses more on physical risks and gives little recognition to the dangers posed to our brain injured members from short term memory loss, fatigue and the many cognitive deficits of a brain injury.

b. what examples can you provide of this differentiation working well? Please detail the parts of the WCA that contribute to this and provide supporting evidence.

We have no information to provide in this section.

Q) For those people with more severe and enduring Mental Health conditions or severe Learning Difficulties:

a. are there parts of the WCA process that you feel are particularly difficult to navigate? Please provide details of how this could be improved, and any supporting evidence that this would be effective.

As reflected in our answers to the previous questions, there are serious difficulties navigating the WCA process from the initial application and ESA50 through to the face-to-face assessment and appeals process. Many people with brain injury require specialist, intensive support to navigate through an ESA claim or review, and the WCA process provides little in the way of guidance to help them get this.

High levels of concentration and attention are required in the face-to-face assessment and at appeals tribunal, and the brain injury may affect a claimant's ability here. A problem is that a missing answer is often seen as indicating no issues with a particular activity, with assessors rarely taking time to look deeper into a person's problems and why they may be experiencing difficulty with an assessment.

A severe or moderate brain injury, and often even a minor brain injury, is a life-long condition that causes a complex array of cognitive, emotional, behavioural and physical effects. We appreciate that the WCA is a functional assessment of a person's ability to carry out essential work-related tasks, but it does not take account of many effects of a brain injury, nor does it account for the often fluctuating nature of the condition.

We would re-iterate our call, raised in previous reviews, for people with brain injury to be assessed only by specialists in this field, or at least for 'brain injury champions' to be available, distinct from 'mental health champions', to provide specialist support to assessors and decision makers.

Additionally, DWP decision maker should, on receiving a brain injury claim, take a more pro-active role in supporting the claimant through the process.

b. are there parts of the WCA process that you do feel support people well? Please provide supporting evidence.

We have no information to provide in this section.

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)
- 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