



Calling for disability assessments to be

# Right First Time



the brain injury association

Headway is calling for urgent changes to disability assessments to reduce the number of vulnerable people forced to go through stressful and often unnecessary appeals processes. Decisions on disability benefits should be **Right First Time**.

1. Assessments should be conducted by people with expert knowledge of complex conditions such as brain injury. In our survey, only 29% of ESA claimants felt their assessor understood brain injury.
2. Audio or visual recording of the face-to-face assessment should be offered as standard to all applicants. They should not have to make special arrangements or provide their own recording equipment for this.
3. A new transparent system must be put in place to reassure applicants that medical and other evidence has been taken into account.



## Headway's survey findings

When we asked brain injury survivors, their families and carers to tell us about their experiences of applying for Employment Support Allowance (ESA) and Personal Independence Payments (PIP), we were overwhelmed by the responses. We were told many moving stories about individual experiences which brought home why disability assessments need to be Right First Time.

Over 650 people contributed their experiences to our survey, with many people applying for both ESA and PIP.

People told us about the financial, emotional and psychological stress of making an application and going through the assessment. As well as the length of time their claims had taken to be finalised, people told us about the fear that they would lose existing benefits.

There was widespread anxiety that, because the effects of brain injury can often be hidden and fluctuating, their brain injury and its effects would not be understood, and that they would not be believed.



"It took three weeks to fill in the form, the questions were not specific to the challenges of changes in perception, fatigue, confusion."

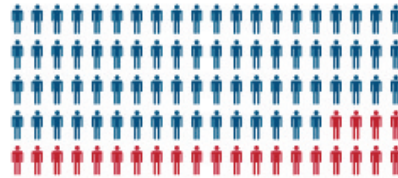
- ESA claimant with brain injury

"After completing three or four 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 one checking what I had done before I could do some more."

- ESA claimant with brain injury

## Employment Support Allowance

76% of respondents said it was difficult to explain the effects of their brain injury on the form



"I felt the assessment took my brain injury into account."

■ Yes (31%) ■ No (69%)



Do you feel your assessor understood brain injury?

■ Yes (29%) ■ No (71%)



Should assessments be recorded?

■ Yes (64%) ■ No (7%) ■ Not sure (29%)



## When it *isn't* Right First Time

Cheryl and Andy had just found out they were expecting their first baby when Andy (36) was hit by a car. He spent three weeks in a coma and was left unable to walk, talk or feed himself.

Although his employers wanted to support him, Andy's doctor told him he was not ready to return to work completely. But the DWP insisted Andy was capable of getting another job instead, and stopped his ESA.

Cheryl had to complete Andy's ESA forms for him. She said: "The assessment should be tailored to suit disabilities such as brain injury. I wasn't asked about Andy's brain injury during the assessment process, I was just ticking boxes."

"During the face-to-face assessment, Andy was asked to fold a piece of paper in half and stand on one leg. These tests showed a lack of understanding about the complex nature of brain injury."

"You've got no idea how the brain injury will affect survivors from one day to the next, and it's very difficult to convey that through the assessment process."



"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 first time!"

- PIP claimant with brain injury

"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."

# Personal Independence Payment

77% said it was difficult to explain the effects of their brain injury on the form



"I felt the assessment took my brain injury into account."

■ Yes (40%) ■ No (60%)



Do you feel your assessor understood brain injury?

■ Yes (40%) ■ No (60%)



Should assessments be recorded?

■ Yes (59%) ■ No (9%) ■ Don't know (32%)



## When it *isn't* Right First Time

Jenny (43) was grooming a horse at work when she fell and hit her head. After life-saving surgery for severe bleeding on the brain, she was left with fatigue, seizures, epilepsy, memory and cognitive issues. She was advised to apply for PIP.

Jenny's first assessment was with a former stroke nurse who understood the complex nature of brain injury. But Jenny then developed hyperacusis, an acute intolerance to everyday sounds. She was sent for a PIP reassessment.

Jenny felt the second assessor didn't understand brain injury: "I eventually broke down and cried. There was a complete lack of empathy. I felt the assessor put words in my mouth and didn't take the time to listen to, or want to understand, me or my mum. It felt like a soulless box ticking exercise. We left feeling intimidated and degraded."



Jenny wants all assessments to be recorded. She says: "There were things in my report which we cannot remember saying at all or that just didn't make sense. Large parts of it were simply inaccurate. If they were recorded, everyone could have a copy and be 100% sure what happened. People deserve the process to be transparent."



# About acquired brain injury (ABI)

ABI is an injury to the brain which has occurred since birth. The effects can be devastating and last a lifetime. It can affect every aspect of a person, changing their personality, relationship and future in an instant.

Around 350,000 people are admitted to hospital annually with a diagnosis of acquired brain injury (ABI) as a result of trauma, stroke, tumour, or illness. The majority will require some form of support or rehabilitation.

Survivors of more severe brain injury are likely to have long-term problems affecting their personality, relationships and ability to live independently. Even with rehabilitation and support, survivors and their families may well face uncertain and challenging futures.

The often hidden, complex and fluctuating nature of ABI can often lead to the person not getting the help and support they need. The cognitive, psychological, emotional and behavioural effects of brain injury can be difficult to detect, particularly by those who have not had specialist training.

## About Headway

Headway works to improve life after brain injury by providing services, support and information at every stage of the care pathway.

Over 120 Headway groups and branches across the UK provide local services to ABI survivors.

Headway's UK services include

- Brain Injury Identity Card - to help brain injury survivors in conversations with the police or everyday social situations
- Free to call helpline, answering more than 10,000 enquiries annually
- Emergency Fund, providing financial support in the immediate aftermath of a brain injury to help with unexpected costs
- Award-winning publications covering symptoms and practical issues associated with brain injury.
- Headway Acute Trauma Support (HATS) nurses, giving families emotional and practical support, information and advice in the early stages following an ABI-related diagnosis.

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