Headway the Brain Injury Association

Response to the Government’s DLA Reform Consultation

About Brain Injury and Headway

Each year as many as one million people attending hospital in the UK will have sustained a traumatic brain injury. Of these, about 135,000 are admitted to hospital due to the severity of their injury. It is estimated that across the UK there are around 500,000 people (aged 16 - 74) living with long term disabilities as a result of traumatic brain injury. The most common causes of traumatic brain injury are road traffic collisions, accidents during leisure or work, assaults and falls.

Added to this, there are many thousands of people living with the effects of acquired brain injury from other causes such as stroke, haemorrhage, meningitis, encephalitis and brain tumour.

The effects of brain injury are wide ranging and can result in complex physical, cognitive and social disabilities. Individuals may also experience changes in emotions and behaviour and may lack awareness of how they have been changed by their brain injury, making it very difficult for families to cope.

Please see the appendix at the end of this consultation for further details.

Headway is a national charity that aims to promote understanding of all aspects of brain injury and provide information, support and services to individuals with a brain injury, their families and carers.

A network of 117 local groups and branches operates across the UK, providing a wide range of services including rehabilitation programs, social reintegration, outreach, carer support and respite. Nationally, Headway UK provides support to groups and branches and helps to deliver high-quality services through guidance on policies, procedures, standards and training. We also have a free national helpline, which provides support, information and signposting to appropriate services.

Consultation Response Overview

Headway welcomes any Government proposals which offer people with disabilities greater choice, involvement and control over their lives. We also believe in operating a welfare system which is sustainable, fair and accessible for those who are unable to work through no choice of their own.
Disability is a barrier to many people. It restricts both inclusion and independence within our society. Again, we welcome any opportunity in helping to shape how changes will be made at local and national level and look favourably upon the laudable elements within this Consultation for people to have improved support, and to be able to participate in leading an active and fulfilled life, as much as they possibly can.

However, offering greater choices is all very well, but in reality we have some grave concerns about the impact of the Coalition Governments’ intention to cut billions of pounds from the benefit system, which will have a huge impact on many vulnerable people who currently access and rely upon these benefits as a must to achieve any semblance of quality of life.

Survivors of brain injury already face many tough challenges in accessing the correct support, specialist services and understanding of their condition. Often referred to as the hidden disability, due to the fact that the brain is damaged yet often with no visible physical disabilities evident, many people are incorrectly considered as being fine when they are not, something which needs to be substantiated through medical records and neurological assessments and not by an appointed GP on a review panel who has little neurological expertise. Very often the cognitive, emotional and behavioural effects of brain injury are only apparent over time and the full impact on day-to-day life is an extremely complex thing to assess.

We also have concerns that the Government’s aim to target some of society’s most vulnerable people who often lack the capacity to stand-up for their own rights, will have a significant and detrimental longer-term impact on the quality of people’s lives, their human rights and mental health as the number of UK citizens classed as ‘poor’ increases.

Due the very nature and complexity of acquired brain injury, many survivors have always lacked choices, particularly within the specialist clinical support and community rehabilitation services postcode lottery. Once again we find our members having to fight for services by defending injuries which have thrown many people into life changing situations and further anguish.

We would like to see real choices for people who need it most, not a financial smokescreen for unrealistic and arbitrary financial measures which places vulnerable individuals on the stand under the guilty until proven innocent system.
Consultation Response Findings

Headway is a service-user led organisation. As such, and in conjunction with brain injury survivors, families and carers, we have held a number of consultation meetings during January and February. The following section contains the detailed and in-depth findings from many of our members, who participated because they are genuinely worried that this reform will remove their freedom of choice to live an independent life.

Question 1

*What things stop disabled people joining in with other people and living full, active and independent lives?*

Effects of brain injury are wide-ranging. People with an Acquired brain injury (ABI) continue to experience many barriers which prevent them from accessing mainstream services and taking part in everyday activities, including memory problems, the inability to process information, low self confidence and esteem, confusion, difficult and/or challenging behaviour, physical difficulties, such as lack of mobility or poor co-ordination, fatigue and speech and communication problems. These are some of the most common consequences of having sustained an acquired brain injury (ABI). This group also has many psychological problems which are often difficult for people to understand and work with, and these include anxiety and depression, anger, repetitive and impulsive behaviour, disinhibition and a lack of emotional literacy.

Research shows that many people with an ABI feel stigmatised and this, in the main, is due to a lack of understanding of ABI, resulting in negative attitudes and discrimination. This lack of understanding can compound feelings of anxiety, low self esteem and confidence which can often cause people with an ABI to feel embarrassed, de-motivated and unable to cope with normal day to day activities. ABI is very often a hidden disability, and is therefore not easily recognisable, which leads to negative attitudes and discrimination.

*Additional comments from our service user panel*

The very fact of being disabled is also a stigma! Prejudice and pre-determined judgement from others is a big issue as people can be frightened or not sure how to
speak to someone with a disability, often leaves both having to overcompensate by becoming overly friendly or just avoiding the person altogether.

Difficulties with speech (having conversations in particular) is a big issue for people with brain injury, as generally, people are impatient when it takes someone longer to say something. This is often due to the brains inability to process too much information at one time (overload) or not being able to separate and process the information being passed.

Fear is also a barrier for many people! Fear of being looked down upon and just because you are in a wheelchair, people assume that you are stupid, when you just need longer to respond to questions and communicate. This ties in with public perception that if there is no physical signs of disability (hidden disability) then there’s nothing wrong or its a mental health problem, which of course brain injury is not.

There are also external physical barriers and these include inappropriate services or services which are unable to meet the complex needs of this client group. Many services are provided in more central locations and transport is a major problem for people with an ABI, as public transport in very often not an option given problems with fatigue, memory, poor planning, anxiety low self confidence and anxiety, therefore many people have to rely on taxis or being escorted and support to take part in daily living activities. This level of support incurs additional costs.

For wheelchair users, access to certain places (even disabled access premises), are not always good with no apparent standardised models. Pavements are often difficult to navigate (not enough dipped areas to get on and off kerb in a wheelchair) and although it can still be difficult for you to use public transport alone.

For carers, the level of disability, lack of external assistance and lack of money all play a huge part in how active their loved ones lives are. Family members assume more responsibility, which puts pressure on all the family and not only curtails the quality and style of living, but affects individuals’ ability to participate in leading, independent everyday life - especially if carers feel overwhelmed.

Question 2.

What parts of Disability Living Allowance do you think we should keep?

Both the care component and the mobility component should be retained as people with an ABI require additional support for these everyday living tasks. The advantage of having two components to Disability Living Allowance is that this provides an
opportunity for people to receive additional, tailored financial support to help them meet their personal care and their mobility needs. This flexibility is essential to maximise independence and reduce costs to society.

The current three levels of award for both the care component and the mobility component recognise individual levels of need and can then tailor awards to meet the individual needs of each claimant. Claimants who have a lower level of need will no longer qualify for benefits. We firmly believe that this will have a negative impact on their health and quality of life.

Additional comments from our service user panel

Currently the lower levels of both components provide some level of additional financial support to assist disabled people with low levels of need. This financial support allows this group of people to participate in mainstream society. If however, these rates were removed, this group of disabled people will potentially not qualify for the first level of PIP which will be hugely detrimental to their quality of life and will exclude them from taking part in many everyday activities. In addition, by removing the first level of award this will place a far greater financial burden on carers and the limiting opportunities for any respite, which will obviously have an impact on their ability to take part in community life, resulting in carers also being excluded from mainstream society.

“We need to have a sense of dignity about our benefit entitlement – we have the same needs as other people as well as additional problems caused by our disabilities. It is only if our needs are met that we are able to participate fully in society. Not having sufficient funds can isolate us further – this has always been a problem with ABI anyway”.

Question 3

What extra things do disabled people need to spend money on?

We are concerned that attempting to quantify the additional costs of disability goes against the founding principles of DLA. Cost of living is directly proportional to severity of disability, so this should be the single most important factor when assessing for PIP. It is important that where a disabled person is receiving free care, such as help shopping, cooking etc., from family members, this doesn’t adversely affect their entitlement to this benefit.
People with an ABI require support with many if not all daily living tasks and this support often requires to be paid for. Independent travel is not an option for many people and public transport is not accessible due to the many cognitive and physical deficits mentioned previously, taxis or supported travel are the only realistic options available to this client group and there are huge costs attached to these. Due to lack of mobility, people with an ABI incur higher household costs in terms of heating, fuel, clothing and related expenses. If able to go on holiday, additional financial costs such as booking airline seats for themselves and potentially multiple, essential, carers are incurred.

**Additional comments from our service user panel**

There are many daily living activities that people with an ABI require support with, including shopping, laundry, preparing and cooking meals, additional food costs, housekeeping chores, paying bills and keeping various appointments all recognised as everyday activities. Also, prescription costs can be high, as can the cost of adapting a home to be suitable, for instance installing chair lifts, hoists, hearing loops, personal safety alarms etc. Food costs are very often also higher for disabled people as due to various deficits they are unable to cook meals from scratch and rely heavily on pre-prepared food. Leisure pursuits also have huge cost implications, travel, support and the additional cost of having a carer or support worker in attendance, i.e. cinema costs are doubled, as are entrance fees to many other leisure facilities.

In rural communities, the issues with social exclusion, transport and general lack of community services, particularly respite, results in full time carers being paid to come and care for the person, which is a huge additional cost.

**Question 4.**

*The new benefit will have 2 amounts for each of the 2 parts of the benefit. Do you think this will make the benefit easier to understand and also easier for us to run.*

Whilst the simplification of the benefit could, in theory, make it easier to administer, the reduction in the number of components, particularly in the ‘Care’ component, will potentially stop a lot of people who currently benefit from and need the lower rate of DLA from receiving it.

The risk is that it will make it less equal and that some people will get a high rate of benefit and others nothing. The proposed changes will result in the new benefit being
less appropriate to each individual and will result in fewer people being entitled to the benefit.

There are concerns regarding the current “main meal” assessment as this is one of the main criteria for awarding benefit and does not accurately reflect the support people with an ABI require to enable them to carry out this everyday activity. Help with planning a meal, supported travel to purchase food and food preparation all require a high level of support. Assessing only the ability to cook a meal does not reflect the high level of support needed to complete this task and is a crude judgement of people’s abilities.

Due to the many cognitive impairments that most people with an ABI have, we would suggest that it will be a huge struggle for many people who are unable to process and hold information, to complete the application form without require assistance.

The application process for DLA is a standard application form and does not provide the scope for people with an ABI to provide information on the level of disability they have. There is also no opportunity to provide information on cognitive deficits - the most common consequence of having a brain injury. It is appreciated that it is unrealistic to have an application form which reflects the full range of medical conditions and/or disabilities; therefore there is a reliance on the assessment process, which many people perceive as being inconsistent, unfair and very often inaccurate.

The main reason for lack of understanding of DLA is the inconsistency in the current assessment and award process. There is strong view that the assessment panels do not have the level of expertise required to assess the complexities of ABI. And many people feel that GPs do not have the required level of knowledge or expertise to make appropriate assessments. This inconsistency impacts on people’s ability to understand the application process rather than the problem being with completing the application form. There is a strongly held view amongst people with an ABI that a neurologist, neuropsychologist or neuropsychiatrist should be a member of any assessment panel when assessing people with an ABI, in order that a accurate and safe assessment can be made.

*Do you think just having 2 amounts for each part will cause any problems?*

Having two different levels of award for each component part of the benefit does recognise that people with certain conditions will have varying degrees of similar needs and the amount of benefit should reflect this. Again, unless there is a clearer and consistent assessment, appeal and award process, then there will continue to
be confusion and lack of public confidence in the process of allocating DLA and the new Personal Independence Payments.

By removing one level of award as with the current system, some people with disabilities will lose benefits, which will have a massive impact on their quality of life. As the form very much focuses on the physical aspects of disability (which as already mentioned, not everyone with ABI will have), many people with cognitive problems that affect their ability to get around and participate in society will go unrecognised. We would suggest that it could also be potentially harder for those currently on the low or middle rates to get the benefit at all, which would result in even greater financial hardship for this particular group of disabled people and their carers.

People who already claim the lower rates of DLA are awarded the benefit on the basis of need – this need will not go away simply because the lower rate has been withdrawn.

**Question 5**

*Do you think that some health conditions or disabilities should allow people to get an amount of benefit automatically?*

We think it would be fair to assess each claim on the basis of need, as long as the assessments are carried out fairly by professional with expertise in the condition concerned. If someone has an obvious condition which is regarded as a long term condition and the prognosis for that condition is that it will not improve with time, then reassessment is clearly not necessary.

**Additional comments from our service user panel**

What can improve in the longer term is how people with these conditions learn to cope with their disabilities, and DLA has been instrumental in improving people’s quality of life by allowing them to have the financial freedom to lead a more independent life. People who have sustained an ABI will not always be able to regain brain function; therefore the cognitive and mobility deficits will not be regained through time. People with an ABI will require ongoing support both from a physical, emotional and psychological perspective with their disability being life-long condition. As such, there should be automatic entitlement to DLA and the new Personal Independence Payment. As already mentioned throughout this document, an ABI has a massive impact on energy levels, ability to concentrate, anxiety, memory,
planning functions etc. unseen impairments that are difficult to cope with and to evidence on the current forms. The automatic right to DLA should therefore remain for long term medical conditions which are clearly supported by a medical prognosis, and ABI should warrant automatic entitlement. If this was the case then there should be no requirement to have continual assessments and reviews, which causes undue stress and anxiety for people with long term medical conditions, their families and carers. This also incurs an additional higher financial cost to the DWP which is money that could be saved.

Or do you think that all claims should be based on the needs of the person asking for the benefit?

As previously covered, it is important that the claim is based on the needs of the individual as brain injury is complex and varying. However, it is equally important that the DWP apply an individually tailored approach to the assessment and review process, where if a person has been diagnosed with a long term condition with little or no chance of improvement, this is taken into account and the process is made easier.

We believe that the length of time from application to securing DLA payment is unacceptable. The proposal to have a six months qualifying condition does not reflect the fact that some medical conditions have an instant impact on people’s ability to work and function normally. For some conditions such as ABI the medical prognosis is straightforward and depending on the severity, these conditions should not have to meet the six months qualifying period. The length of qualifying period also causes undue financial pressures for carers and families and makes life even more of a struggle, exacerbating the impact of the ABI. This additional financial pressure can often lead to further anxiety, family break-ups and mental health issues.

**Question 6**

*How can we make sure that disabled people who most need the new benefit can get it?*

The only way to ensure that disabled people with long term medical conditions are awarded the new benefit is to have a fair and appropriate assessment process. There is also a recognition that, due to the current assessment process, that there are huge variances in appropriateness of DLA awards. These inconsistencies have led to the general perception that people with the greatest level of need are not being
awarded DLA. We believe that the assessment panel should comprise of people who have an in depth clinical knowledge and experience of the specific condition. By introducing this, the assessment process would promote fairness, equality, consistency and public confidence.

In order to make the assessment transparent and robust, the burden of proof should be placed on the assessment panels rather than the claimant themselves. The medical assessors should be legally obliged to access the level of information they require to enable reliable, safe and consistent decisions on claims. The claimants of DLA and PIP are people who have medical conditions such as ABI and as such, these claimants do not have the capacity or knowledge, to understand the level of information required by the assessment process.

General consensus suggests that the form should also be more accessible, easier to understand and less frightening for people. Assistance and support to complete the forms correctly should also be readily offered by somebody in person. Guidance notes are useless to some people and simply add to the confusion.

The DWP should adopt a far more proactive and fairer role in identifying potential eligible claims and advice should be given from the outset to claimants regarding any other benefits they may be entitled to at the time.

Assessments for benefits should be done before discharge from hospital with information given to families and carers on where to get support and apply for this benefit.

In addition, when awarding contracts to independent medical companies (ATOS) to carry out the required medical assessments, there should be a demonstrative level of knowledge and expertise in complex medical conditions such as ABI. The DWP should require ATOS to use brain injury specialists when making the assessment, similar to the mental health specialist scheme they are implementing in ESA.

We would like to add that assessment should be based around need and not on targets or cost reductions!

What activities or actions are the most important to live an independent life?

To ensure quality of life for a person, it is important to find individualised activities that take into account their personal need, wants and values. It is impossible to find activities that are essential for everyone, except for the very basic human needs such as eating and drinking. This hardly guarantees an increased quality of life or independence.
People should also have the financial stability to take part in the activities they as individuals consider adds to their quality of life. The day to day activities that everyone considers to be the basic essentials of everyday living, getting up in the morning, showering, getting dressed, shopping, cooking, cleaning etc, are activities which people with disabilities should be able to carry out either supported or independently. However, as these basic tasks very often incur costs for the disabled person, these costs should be viewed as being basic requirements.

Having the financial freedom to take part in social activities should also be a cornerstone of the new benefit and people should have the right to decide for themselves which social activities they want to participate in. The new benefit should also recognise the fact disabled people will often pay double the amount able bodied people pay to take part in social/recreational activities and this is due to their additional requirements i.e. travel, entrance fees, one to one support etc. So although there are basic requirements which mostly focus on the care needs of disabled people, the social/leisure quality of life, essential requirements of daily living should also be reflected in the new benefit without being too prescriptive. Increasing the number of disabled people who are able to actively participate in society increases the number of people who are contributing to the economy, bringing big financial benefits to the government for a relatively small outlay in the form of a PIP.

One particular quote we received which sums this up is ‘If I was on my own I wouldn’t get up in the morning!’

**Question 7**

*How can we make sure that the new benefit takes into account the way a person’s health condition can change?*

At the moment many of our service users complain that the assessment is only carried out using a form and possibly a visit from an assessor who usually has no specialist knowledge of brain injury. There is no scope for assessing the variable nature of the condition, as it is quite possible they visit on a ‘good’ day and make no further assessments.

It has to be recognised that people with long term medical conditions are unlikely to have substantial changes to their health outcomes, therefore the requirement for these types of conditions to be assessed on a frequent basis is unnecessary and can lead to people becoming distressed and anxious, further exacerbating their medical condition. There are also huge cost implications for carrying out unnecessary reviews to the DWP.
People are taught to be positive during recovery and this can make it difficult to focus on the negatives, and also in many cases after brain injury they lack insight into their own issues.

In an ideal world, the decision would be based on a broad range of opinions, including the claimant and their treating doctors and professionals, as well as family members and carers who see and understand the day-to-day issues.

For people with medical conditions which are not likely to be long term, and are expected to improve through time, then a review process will require to be established. It might very well be appropriate to re-assess these types of “temporary” or short term medical conditions by having an assessment panel process.

It is accepted that there needs to be clear and appropriate review processes but there should be recognition given to long-term medical conditions with lifelong prognosis and for short term conditions. With only short term conditions and an indicative prognosis being subjected to reviews.

Additional comments from our service user panel

Disability/ill health can get worse as you get older, and the benefits system needs to take account of this. Often when you reach a certain age (65) you can no longer access the same services (e.g. day centre) even though they may meet your needs.

Many people use DLA to buy services such as respite, and if unpaid carers lose this they are likely to go into crisis as they will no longer be able to cope.

Question 8

*When a person makes a claim to the new benefit, should we take account of any aids or adaptations that they use?*

No.

We don’t feel that aids and adaptations should be included in the criteria under any circumstances because they are an essential requirement that should be looked at as a separate issue. We feel that punishing people for using aids that increase their independence and quality of life is discriminatory and goes against the social model of disability. The aids and adaptations may help someone to get around independently, but they are of no benefit without financial support. As such, the funding required to purchase aids and adaptation should remain the responsibility of Central Government, and allocated to Councils and health authorities on an equitable basis, based on local levels of need.
Reducing a person’s income because they successfully use mobility aids promotes the dangerous situation where people are reluctant to take up the wheelchairs, crutches, walking sticks etc that could increase their independence and safety.

Additional comments from our service user panel

“Even if someone uses a wheelchair it does not mean they can get out and about successfully alone. This is dependent on many things from whether you can get over the front door to the proximity and accessibility of transport”.

What aids and adaptations should we take into account?

We feel it is totally unacceptable and discriminatory, to require people to use specific aids and equipment. Decisions concerning equipment are, and must be, outside the scope of the DWP – this is a decision that must stay between the patient and their medical professionals, and not based on a benefits claim.

Should we only take aids and adaptation into account if the person already uses them?

Accurate OT assessments should result in aids and adaptation which are needed by disabled people to assist with their mobility. There could be some reluctance by people to use the aids and adaptations even although they have been assessed as needing them for a variety of reasons, including independence, a reluctance to become reliant upon them, and denial that aids and adaptations are required. We find the suggestion that this could have a negative impact on the level of award offered as wholly unacceptable.

Or should we take aids and adaptations into account that a person could use and get hold of easily.

This should not be part of the assessment process. The sole purpose of an OT assessment is to identify which aids and adaptations are required by people, therefore any aids and adaptations supplied should be based on the level of need.

We reject any suggestion that the level of benefit should be influenced by a person’s successful use of aids and adaptations, or be part of the assessment for PIP. As above, decisions concerning equipment are, and must be, outside the scope of the
DWP – this is a decision that must stay between the patient and their medical professionals, and not based on a benefits claim.

If the DWP insist on implementing this change, there should be an independent consultation on the logistics of transferring these responsibilities from Social Services to DWP appointed assessments.

**Question 9.**

*How could we make the way a person asks for benefit better?*

*For example.*

*How could we make the claim form easier to fill in?*

We recognise the benefits of the current form, however we receive many comments that it is very long and difficult to understand. It also doesn’t necessarily allow space for the full list of brain injury symptoms given earlier. It needs to be written in plain English and we would welcome a section specifically for brain injury which recognises the unique challenges of this condition which differ from their long term and progressive neurological conditions.

We feel the best approach to make the process less complex and intimidating would be to ensure access to appropriate specialist advocacy and support services to complete the full assessment process.

*Additional comments from our service user panel*

Some suggestions as to how this could be improved are; to make the form smaller; include more cognitive questions; remove any jargon; ask fewer repetitive “trick” questions and remove demeaning questions such as how many times and for how long do you need support with toileting at night?

It should also recognise that some people with an ABI have communication deficits and difficulties in processing information, co-ordination, poor memory, confusion and anxiety and will therefore, require support to complete the application form. This support should be offered/provided automatically for people with ABI when making an application. Often it is a carer that fills in the form. Individuals should be able to nominate someone to fill in their form on their behalf who can then deal with it all.

The application completion stage should also include benefits advice, as there could be additional benefits people are eligible to, but they (or their carers) are not aware
This support should be provided at the first stage of the application process where claimants are invited to attend an initial interview and signposted onto an independent benefits advisor or welfare rights worker and not referred to a benefits helpline, which is not appropriate to someone with an ABI. This would also relieve the pressure that many carers are put under, as they very often have to assume the responsibility of completing the application form. It should not be assumed that carers have the insight to complete these forms.

A quote from one of our members explained how they felt when completing this; “It’s as if the assumption is that people are being dishonest from the start, and the form is trying to catch them out”.

How could we tell people about the new benefit so that they know what the benefit is for and who is likely to get the benefit.

People who are currently in receipt of DLA will have an understanding of the eligibility of the new benefit and prior to the introduction of Personal Independence Payment they should be advised of the changes in the assessment process and levels of award. Benefits advice should be available in GP surgeries, hospitals and social services departments, especially when people have sustained an injury which is likely to leave them unable to return to work, or if an injury will result in the person requiring care. Hospital Social Workers, where accessible, should also be able to signpost people onto benefits advice if they themselves are not able to provide it. Benefits advice and support should also be included in hospital discharge plans, if the person has sustained an injury which will result in a long term medical condition such as an ABI. There should be referral processes established in neurological wards of hospitals, as these patients are the most likely to be unable to work and will have to rely on DLA (PIP). Patients, and more often carers, should be given contact details of independent benefit advisors in their local area, and it would also be possible to hold benefit surgeries periodically within these specialist hospitals.

The difficulty in providing information as to who is likely to get the benefit results from the inconsistencies in awards.

Any and all benefit information must be written in plain language, with information about what the qualifying conditions are, with the required information should clearly identify the components parts to the benefit, and the levels of award. Definitions of mobility and care should be given in the information with examples provided.

Better training for the people who administer the benefits on what’s available and on different conditions (as well as where to access expertise and advice on specific
conditions). TV advertising, information left in hospitals, CAB, community projects (Third Sector organisations), libraries etc.

Question 10

Who are the best people to tell us about the needs of the person asking for the benefit?

We feel evidence from treating doctors, social workers and other specialist brain injury professionals who are directly involved with the claimant and have consulted them recently, are the only reliable professional sources that should be considered here. The DWP should be aware that not every claimant with brain injury has been able to get a professional assessment and the DWP should perhaps consider commissioning one to ensure the quality of their decision making process. For instance, where a person has cognitive, emotional or behavioural problems, a neuropsychological assessment should be available, as well as specialist reports from occupational therapists with a specialism in brain injury, for assessing everyday needs. This should be supported with further evidence from people who have regular daily contact and who knows the person, such as close family members, carers, GP’s and even staff within local Headway’s, or independent living units.

Medical records alone will only provide evidence of someone’s physical deficits, not how they struggle to cope on a day to day basis. The person themselves may have problems with insight, or may not be able to give all the necessary information. They may cover things up as a coping mechanism as they do not want people to know what deficits they are struggling with.

It should not be presupposed that everybody has family or carer support. If someone is isolated or socially excluded to begin with, before sustaining a brain injury (or some other condition), who would support them in completing a DLA form?

It is a fundamental requirement that the medical assessors have the clinical knowledge of the medical condition of the claimant, rather than having a GP complete the assessment. GP’s do not have the level of specialism required to make a sound assessment of complex medical conditions such as ABI and only a neurologist, neuropsychologist or neuropsychiatrist will have a thorough understanding, knowledge, and experience, of the physical and psychological consequences of an ABI. There may be occasions where it is appropriate to liaise with other support services the applicant is accessing, as they will have a practical understanding of the level of ongoing support required and/or is being provided.
The DWP have acknowledged this need for specialist assessors in a limited way, with the forthcoming introduction of mental health champions to ATOS’s team for ESA Work Capability Assessments (as recommended by the Harrington report). This approach must be included in any new PIP assessment, and broadened to include the equally, if not more, complex condition of acquired brain injury.

Additional comments from our service user panel

There was a clear indication that many people with an ABI did not want their GP to be involved in the assessment process, as they felt that they did not fully understand their associated medical and psychological needs, and were on many occasions unable to respond appropriately to their needs.

Many people with an ABI were far more confident in having a neurological clinician involved in all ABI assessments, as they felt that they had the required level of expertise required in this field, and this would ensure that assessments were based on sound knowledge and expertise, rather than “general” judgement. We therefore believe that it is essential that the opinion of at least one brain injury specialist is taken into account.

If however, ABI was to be recognised as a long term medical condition, with the associated prognosis, and the onus of accessing the relevant medical information was placed on the assessors, the number of time consuming and distressing assessments would be removed. This would reduce the massive costs to the DWP associated with medical assessment contracts (ATOS).

What information will we need to make it clear what the person can and cannot do?

As above, the applicants themselves, and people who know the person – both medical and practical opinions from carers, GP, family members, people who see the person in different settings (e.g. at Headway) day to day, people the individual trusts. Again, if the applicant has a long term medical condition such as an ABI, there will be mobility and cognitive deficits that are common to these types of conditions.

Ideally, medical records should identify the cause of the ABI, the prognosis and the effects a person is experiencing. However, because of a lack of specialist services nationwide, we find that often this information is not included. In the case of brain injuries that have long-term complications and would warrant an application for PIP, there should be assessments from neuropsychologists, occupational therapists, physiotherapists, neurologists etc., available. Where these are not available, the
DWP should be looking to commission them as part of their thorough and accurate review process.

When questioning an applicant about their needs, any questions should be direct and clear, and recognise that people with an ABI may have difficulty in processing information. They may also lack insight into their own condition, so any interpretation of their answers should take this into account. The use of hypothetical questions should also be avoided, as this requires people to respond to situations they would not face. The assessment process should be adapted to meet the needs of specific medical conditions, and the questions should reflect that condition rather than having standard questions which will not identify disabilities/deficits or impairments relevant to that condition. For example, the current assessment process does not provide sufficient opportunity to identify the cognitive impairment people have as a result of an ABI.

The current mobility assessment is crude and requires people to carry out basic mobility functions. Again there is no recognition given to cognitive deficits relevant to ABI nor is there any scope in the mobility assessment to recognise psychological problems with affect people’s mobility. The current assessment is entirely based on the “medical” model of mobility with no understanding of the “social” model which would recognise all of the barriers to mobility.

Question 11

An important part of the new benefit may be talking face to face with an independent person about how well you can do the things you need to do to take part in everyday life.

What benefits or difficulties might this bring?

One positive could be that the independent person may offer a different perspective on the person’s life. Having access to social work, welfare rights and/or an advocate for both the form filling and any subsequent visits about it would also be vital to ensure someone with an ABI could give an accurate view of their condition. Carers have very real concerns about the vulnerability of people with an ABI and would only be willing to consider a one to one visit if an additional person representing the client was present.

There are negative aspects of people having to meet on a one to one basis, however, and having to speak to a stranger about impairments and/or deficits as this can be embarrassing for some people. The requirement for a visit will cause distress
and anxiety amongst people with an ABI particularly when there is a communication deficit and this could lead to exacerbated challenging behaviour and anxiety.

A face-to-face discussion does allow the assessor to take much more information about the disability; however they must be aware that the responses may be challenged due to a lack of insight or difficulty communicating, as described in previous answers. Some people may find it hard talking to a stranger about their personal circumstances.

Also be aware that cognitive problems may lead people to forget their assessment appointment, and often to forget the challenges they face on a day-to-day basis. Sometimes with home visits an individual may want to show what they can do, rather than what they cannot, especially if they have never met the assessor before. The assessor may not be qualified to assess the person’s condition. One suggestion is to voice record interviews so that there is a record of the discussion, although this may also be an additional source of stress.

If there is a requirement to have a one to one visit, this should be done by someone suitably qualified in the medical condition of the applicant. The scope of the mobility needs of the claimant should be based on the social model of mobility and not on the traditional medical model, and should involve mobility needs not only within the home environment, but also within the context of the wider social environment.

*Is there any time when it would not be right to say that a person has to meet an independent person fact to face, either in the person’s own home or somewhere else?*

There is enough scientific and medical evidence of the health outcomes of most long term conditions, and the medical evidence of the consequences of an ABI is robust enough to limit the need for one to one visits. If the applicant being assessed has a diagnosed ABI and there is a panel member with a neurological specialism, then the long term effects of having a brain injury should be clear, reducing the requirement for a one to one visit. If an applicant was uncomfortable and had justifiable medical reasons for not wanting a home visit then this should not result in automatic refusal of the benefit. It may be better on these occasions to meet with the carer rather than the claimant themselves.
Additional comments from our service user panel

“Sometimes you can come across, with acquired brain injury, as very capable when you literally have problems crossing the road or telling the difference between the fridge and the cooker”.

“Obvious physical things are easier to assess, if someone has no use of their hand but they could also have cognitive and emotional problems that present more difficulties for them. Anyone who assesses should have expertise in brain injury. The system you operate should be sensitive to this kind of thing”.

**Question 12**

**How should the reviews be carried out?**

The review process should follow the same principals as in question 8. There should be clear review processes established for the new benefit, with appropriate timescales, dependant on the medical condition and expected outcomes. Long term conditions such as ABI are lifelong conditions. This information should have been included as part of the initial assessment process, therefore there should be no need to review these cases. However some long term conditions will be degenerative and, dependant on the level of award made initially, there will be a requirement for a review. However, the DWP could consider introducing a short form to ask if there have been any changes, countersigned by a responsible person involve in the regular care of the claimant.

By establishing prognosis based reviews for short term conditions, this will allow for the identification of those cases when expected medical improvements justify the withdrawal of DLA or Personal Independence Payment, and should reduce the number of fraudulent claims.

Clear information and a robust assessment will reduce people’s reluctance to ask for a voluntary review of their award when their condition deteriorates, or their social situation means they require more support.

**Should there be different types of reviews...?**

As with the previous response, the only fair way of reviewing claims is to base the frequency and depth of the review on the medical condition/prognosis. This will ensure that there is consistency in the review process. Claims which meet the
criteria for long term conditions should not be subjected to any further reviews, unless that condition is expected to deteriorate.

Question 13

*The new benefit will be easier for people to understand, so we will expect people to tell us when things change in their lives.*

*How can we get people to tell us about these changes?*

As mentioned previously, there has in the past been an over reliance on people self reporting changes in their conditions. Given that this could result in a reduction or withdrawal of the benefit it is unrealistic to expect all claimants to self report. Also, some medical conditions are such that the person with the condition will not always recognise changes in their condition, therefore medical records and prognosis should be used for this purpose. By establishing a review process which is based on expected health outcomes and likely improvement or changes, the reliance on self reporting should be removed. Once an award has been made claimants should be advised, at that time, of the review process for their condition i.e. long or short term condition. An added benefit of having a robust review process is that people who do have short term conditions will remain on DLA (PIP) only for as long as their medical conditions warrants.

Question 14

*What types of help and advice are people who will ask for the new benefit likely to need?*

The type of support and advice claimants require will depend on their medical condition/disability and personal circumstances. People with an ABI will require support to complete the application form, and also support to attend the assessment and, if required, the appeal. Applicants with an ABI will have communication, processing information, mobility and co-ordination deficits, which will make completing the application form impossible. There is an opportunity to introduce a staged application process, which will identify those claimants whose medical conditions indicate their inability to complete the application. The first stage of the application process could be a simplified form, which asks the medical conditions of the applicant, and if they are able to complete the more detailed second stage application. For those applicants who indicate they are able to move to the full application stage, and have identified their own support, additional support would be
offered but not required. A signposting service could be provided for those applicants who indicate that they are unable to complete the application form. This would help ensure that the application process gives recognition to the fact that some claimants require additional support.

The types of support which should be available are: advocacy, independent benefits advice or support from a welfare rights worker. Clear, plain English information sheets would also help understanding. This will remove some of the pressure and strain from carers and family members, who are often heavily relied upon to complete application forms.

It would also be useful for people to receive benefits advice whilst still in hospital or residential rehabilitation, if the condition is likely to be long term. This advice could be provided by the hospital Social Worker or an independent benefits advisor/welfare rights worker. The voluntary sector is well placed to offer specialist advice and advocacy services, and using such services would benefit the DWP by reducing the load on their staff, as well as the number of awards made in error. However, this could require additional resources due to the increased number of DLA assessments taking place throughout the country during the migration phase. People are not always able to access the support they require due to an increased demand.

The DWP also needs to be more proactive in advising claimants of any additional benefits they may be entitled to, as very often people do not know what they are entitled to and therefore don’t apply for additional support.

Question 15

*Could some form of requirement to access advice and support where appropriate, help encourage the minority of claimants who might otherwise not take action?*

If it were administered correctly and made use of experienced and specialist professionals in the field of brain injury, this could be an excellent way to support people through the claims process. However, the risk is that inexperienced staff or a focus on deterring people from taking claims forward would create a barrier to independence.

The provision of support and advice should be based on need and choice and to insist that people take help or advice could restrict their personal freedom of choice and independence. Signposting is important, but it does not always mean a person will access the support they require, especially if they lack confidence and motivation. Advocacy services are needed to support people through the whole process to ensure they get what they need.
Question 16

*How do disabled people currently fund their aids and adaptations?*

People currently fund their aids and adaptations in a number of ways: through DLA/ESA/ILF/Direct Payments/Social Care budgets etc., plus their own pockets, credit cards, loans, savings etc. Also help from family members and carers.

Sometimes aids and adaptations are assessed as being needed and funded or part-funded by local authorities. Due to the challenges with local authority funding and a lack of a consistent approach across the UK, the assessment process and allocation of funding varies wildly from area to area. Often councils will make allocation of equipment very low priority, so people are forced to pay for it themselves using the methods above.

In all cases, the provision of aids and adaptations should be in addition to DLA (PIP), not instead of.

It may be useful for people to have an option of receiving a payment in lieu of equipment provided by social services, such as wheelchairs etc., to improve their choice over the equipment they receive, and ongoing service costs. If this is implemented, it must be backed up with support for people to help them spend their money on appropriate equipment, such as occupational therapy services, as well as recognising changing circumstances.

*Addition comments from our service user panel*

There are huge geographic variances in the way people access aids and adaptation and also in how these are funded. In some Council areas people are assessed by Occupational Therapists and are then placed on a waiting list for aids and adaptations. Cases are prioritised and the length of time people can wait also varies hugely. Resources are not distributed equitably across Council areas and this results in some people accessing aids and adaptation fairly quickly whilst others wait unreasonable lengths of time. Some aids and adaptation are fitted at no cost whilst others require a financial contribution from the client, again this is dependant on the resource available. There requires to be a consistent approach to how people access aids and adaptation across Council areas. OT assessments and allocations require to be reviewed and systems which operates similarly across the Country needs to be developed. Funding does require to be allocated to Council and Housing Associations to fund aids and adaptations as people do have the legal right to have an Occupation Assessment carried out. It is unreasonable to have such huge discrepancies on how disabled people access aids and adaptations given that the
allocation of this type of equipment can increase disabled people’s quality of life and their independence.

*Should there be an option to use PIP to meet one off costs...?*

There should be an option to use PIP for a one off cost, as long as it is in addition to the benefit rather than a replacement. This is a personalisation issue in that people should be able to buy the things that they need to have a quality of life, not just exist. It is up to individuals to make this decision, but it shouldn’t mean that they lose out on other entitlements because they are on DLA.

As far as aids and adaptations are concerned, it should remain the responsibility of Central Government to fund these, with clear and consistent assessment and allocation processes applied across Councils. For those applicants who reside in private houses, aids and adaptations should be funded via Social Services with an allocation from councils. Disabled people who are eligible for Personal Independence Payment should not be required to fund the installation of aids and adaptations from their allowance. DLA is currently not means tested, and it is proposed that the new PIP will remain the same; therefore it is unreasonable to expect disabled people to fund aids and adaptations from this allowance, unless they are given an additional amount included in their award to fund this.

**Question 17**

*Support for children*

n/a

Headway provides support for adults with ABI.

**Question 18**

*How important or useful has DLA been at getting disabled people access to other services or entitlements?*

DLA has been critically important, as it passports people onto additional benefits, which has resulted in a better quality of life.
Additional comments from our service user panel

There is an inconsistency in allocating bus passes, and only those who qualified for the middle and higher components receive bus passes. For those disabled people who can access public transport, the travel card has huge benefits, and assists people to get out and about at a reduced cost. For other disabled people who have used their mobility component to fund a car, this has greatly increased their independence to get about. It would useful to review the issue of travel cards with the introduction of the new benefit; as part of the assessment process it should be established if applicants are able to use public transport and would wish to access a travel card. This would lead to greater social opportunities and increased independence.

Are there things which could be done to improve these passporting arrangements?

DLA or the new PIP should be a passport for free prescriptions and eye care as currently only those people on income support receive free prescriptions and eye care. DLA and the new PIP is a benefit which recognises that people have a medical condition yet they are required to pay for prescriptions and eye care. Many if not all people with a long term condition will require to take medication for long periods of time and the cost of their medication can be a financial burden. Given the fact that DLA is a benefit based on people’s medical needs, is it not appropriate that they also receive free prescriptions and eye care? ABI is a condition which can very often require people to take various types of medication for life; some people who have sustained ABI also have problems with their vision which will requires ongoing medical treatment. Given that ABI results in restricted mobility and also can have an impact on core body temperature particularly if the pituitary gland has been damaged, it would also seem appropriate that people in receipt of DLA or PIP are automatically entitled to the winter fuel allowance.

Additional comments from our service user panel

"Crucial passport to concession travel, blue badge scheme, other benefits such as income support through disability premiums and thus free prescriptions, and housing and council tax benefit amongst other things. These things all help us live a proper life in the community. They enable us to make best use of services and to meet up with our peers and friends, to take part in activities, be volunteers, work, look after our families".
“if we did not automatically get help we would be excluded from many of the things non disabled people take for granted. This would not be fair –we would not be being treated as equal members of society”.

“The Warm Front scheme is only for people over 60, which is discriminator, as people of any age can sustain an ABI. And for many people who have sustained an ABI this can severely restricted their mobility which has an adverse effect on their ability to “keep warm”.

Question 19

What would be the implications for disabled people and service providers if it was not possible for PIP payment to be used as a passport to other benefits and services?  

This would increase administration costs across services by duplicating assessments. It would be inadvisable to consider changing this. People benefit greatly from the current DLA system which entitles them to many other services and benefits. The DWP benefits greatly from this streamlining of the system and reduction in assessments required.

Additional comments from our service user panel

The blue badge scheme is particularly popular with disabled people as it gives them priority over a parking space, which helps disabled people to take part in everyday activities. Disabled people who have limited mobility benefit from the blue badge scheme as they are able to be more independent than they would be if this was to be withdrawn.

The Warm Front Scheme is less well known amongst disabled people and does need to be publicised more. The Warm Front Scheme give recognition to the need to assist disabled people to keep their homes warm. Also including an automatic entitlement to the Winter Fuel Allowance would provide further support to disabled people to help with fuel costs, particularly when there is a likelihood of severe weather. The withdrawal of the Warm Front Scheme would obviously result in increased heating costs for disabled people, who due to their medical condition and restricted mobility, are less able to keep themselves warm, and therefore incur higher heating costs. The withdrawal of these existing additional benefits would have a detrimental impact on disabled people’s quality of life. It would also result in inconsistency in awarding this additional support, and would lead onto devolved
assessment processes which would be budget driven and not based on the needs of applicants.

**Question 20**

*What different assessments for disability benefits or services could be combined and what information about the disabled person could be shared to minimise bureaucracy and duplication?*

It might be beneficial to share information with regards to social care funding and eventually personal health budgets, to ease the burden of assessment, but under no circumstances should this happen automatically. Benefits such ESA have a different focus, so it is hard to see how the assessments could be combined, however it may be useful for decision makers to have access to previous assessments with consent of the individual.

Given the depth of personal information which will be gathered during the DLA (PIP) application/assessment process disabled people are reluctant to authorise the automatic entitlement to share their information, unless they have prior knowledge of who the information will be shared with, and the purpose of it. There should not be an automatic right to share the information gathered through either the application or assessment process, without the full consent of the applicant.

**Question 21**

*What impact could our proposals have on the different equality groups and what else should be considered?*

We support any policy which promotes equality and endeavours to prevent discrimination. We acknowledge that some groups are harder to reach and may not be aware of their entitlement to disability benefits. Therefore we support advocacy services to assist people to make informed decisions.

There is the possibility of discrimination due to the proposal to remove the care component of the new PIP benefit from children and also from people in nursing care, if they are not paying for this care themselves. If someone is in nursing care or a care home there should be no difference in eligibility to the care component irrespective of the care is paid for, all awards should be based on needs and not financial circumstances. Also, if the proposal to remove the lower rates for both mobility and care is implemented, this will result in a high number of people with disabilities being discriminated against. To remove the lower rates from the new PIP
will result in high numbers of disabled people being taken off benefits, in order to achieve budget savings. If there are robust application, assessment and review processes established, which are based on medical/professional/carer evidence and expertise, this should result in awards being made which are based solely on need and are consistent in practice. The current system which is based mainly on a judgement process by the assessors, rather than on sound medical/professional/carer expertise, is viewed as being inconsistent and flawed by the general public. Therefore disabled people are viewed as being discriminated against by the current system.

Information must be made available to all BME groups in any format and language they require, to avoid exclusion.

Additional comments from our service user panel

“It seems as if this whole change is not to do with trying to make things better for people with disabilities but only to cut the benefits budget by making things more difficult for us. Life is hard enough. People are very frightened by this. Has the cost of all these ATOS employed “healthcare professionals” and the cost of tribunals been taken into account. We feel that we are being doubly affected, by cuts to benefits and cuts to local authority services”.

Question 22

Is there anything else you would like to tell us about the proposals in this public consultation?

There is a danger that by changing the current systems it may actually become more complex and exclude some deserving people with a disability. It is important to recognise that brain injury is a specialist area and there are a number of “hidden” residual effects after a brain injury that may be missed without the claimant receiving support during their assessment.

We call upon the DWP to ensure that decision makers and assessors are given adequate training to help them fully understand this complex disability. We hope that you take this opportunity to create a benefit that can take into account the needs of our service users, while ensuring that all people who need support receive it.
Appendix

About brain injury

Our brain is the part of our body that determines everything about us - what we think, what we do and who we are. Yet it can be damaged very easily. The brain is protected only by the bone of our skull, and may be injured even when there is no obvious external damage to the head.

What we call a ‘traumatic brain injury’ is the result of a severe blow or jolt to the head, for example in an accident, fall or assault. Other common causes of brain injury include stroke, haemorrhage and infection. Injuries like these are known as ‘acquired brain injury’.

What are the effects of brain injury?

The problems resulting from brain injury may not be obvious to other people. Because of this it is often referred to as a ‘hidden disability’.

Brain injury can, however, completely change the lives of the person with the brain injury and those around them.

The effects are complex and vary from person to person. Common effects include:

- 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

Brain injury facts and figures

Traumatic brain injury

- Each year an estimated 1 million people attend hospital A&E in the UK following head injury. Many more head injuries go unreported and are not assessed by medical professionals
Of these, around 135,000 people are admitted to hospital each year as a consequence of brain injury

It is estimated that across the UK there are around 500,000 people (aged 16 - 74) living with long term disabilities as a result of traumatic brain injury

Approximately 85% of traumatic brain injuries are classified as minor, 10% as moderate and 5% as severe

Men are two to three times more likely to have a traumatic brain injury than women. This increases to five times more likely in the 15-29 age range

Life expectancy for brain injury survivors is normal, so over time, what may seem like a low volume problem becomes a high volume one

Other forms of acquired brain injury

Over 130,000 people have a stroke each year in England and Wales

There are estimated to be over 450,000 people in England living with severe disability as the result of a stroke

An estimated 13,000 people are diagnosed with a brain tumour each year in the UK

As many as 500,000 people living in the UK today have had either viral or bacterial meningitis at some time in their lives

Common causes of hypoxic/anoxic injury include heart attack, suicide attempts, near-drowning, electrocution, drug overdose and exposure to toxic substances
Headway – the brain injury association

Response to the Work and Pensions Committee inquiry into proposals to replace DLA with PIP - July 2011

Background info on Headway and also links to the UN Convention on rights for Disabled people (UN CRDP)

About brain injury and Headway

1. Each year an estimated 1 million people attend hospital in the UK following head injury. Of these, about 135,000 are admitted to hospital each year as a consequence of brain injury. It is estimated that across the UK there are around 500,000 people (aged 16-74) living with long-term disabilities as a result of traumatic brain injury. The most common causes of traumatic brain injury are road traffic collisions, accidents during leisure or work, assaults and falls.

2. Added to this, there are many thousands of people living with the effects of acquired brain injury from other causes such as stroke, haemorrhage, meningitis, encephalitis and brain tumour.

3. The effects of brain injury are wide ranging and can result in complex physical, cognitive and social disabilities. Individuals may also experience changes in emotions and behaviour and may lack awareness of how they have been changed by their brain injury, making it very difficult for families to cope.

4. Please see the appendix at the end of this consultation for further details.

5. Headway is a national charity that aims to promote understanding of all aspects of brain injury and provide information, support and services to individuals with a brain injury, their families and carers.

6. A network of 117 local groups and branches operates across the UK, providing a wide range of services including rehabilitation programs, social reintegration, outreach, carer support and respite. Nationally, Headway UK provides support to groups and branches and helps to deliver high-quality services through guidance on policies, procedures, standards and training. We also have a free national helpline, which provides support, information and signposting to appropriate services.

7. At the time of the Work and Pensions Committee inquiry into proposals to replace DLA with PIP, Central Government have just completed a consultation on the UN Convention on Rights to Disabled People (UN CRDP) and where appropriate we have made links to Convention and the articles contained within.
Welfare Reform

8 The replacement for Disability Living Allowance (Personal Independence Payment (PIP)) aims to cut the amount paid to working age adults by 20%, but it is likely that many more than 20% of disabled people will be subject to loss of this benefit because of new eligibility assessment measures and a change from three to two main rates of payment1 (that continue to include both care and mobility components)2.

9 The DWP’s proposed assessment criteria for the new PIP takes wider provision into account e.g. it looks less at the ‘ability to walk’ and more at the ability to ‘get around’; e.g. if someone can use a wheelchair independently, they would be deemed to have the ability to ‘get around’. It neither factors in costs of procuring nor maintaining manual aids e.g. equipment used to transfer from wheelchair to chair, the wider environment or the effects on the person using them (articles 19 & 20). It also takes no account of aids such as cars or scooters that a disabled person may need to live an active and independent life – aids which DLA currently supports.

10 Importantly, the new benefit still takes very little account of a person’s cognitive disability with regards to their ability to get around – someone who is physically very able can easily be incapacitated by their cognitive problems, meaning they are unable to plan, initiate and complete a journey without continual support.

11 A key concern we have heard is that the new PIP may provide for disabled people to ‘survive’, but not to ‘live’ (see, 2.9).

12 Work capability assessments have been criticised because they do not take into account mental health and fluctuating conditions as well as physical impairments. There is fear that the new PIP assessments will do the same.

13 Other categories in the proposed criteria also would also ignore effects or costs associated with impairments/conditions, by focusing narrowly on tasks that would restrict independent living. The criteria fail to consider reductions and constraints on other budgets and the individual freedom afforded by DLA currently, to top-up/purchase more suitable provision than is available through statutory organisations (Articles 5 and 28).

14 A recent report published by the Citizens’ Advice Bureau (CAB, 2011) provides evidence and testimony on unfair and inadequate health assessments undertaken through Work Capability Assessments for Employment and Support Allowance (ESA). ‘Scottish CAB have advised many clients who have been found fit

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1 At the time of writing the impact of the change from three to two rates of pay remains unclear, and this is further complicated because the DWP have not yet allocated scores to the descriptors to be used to assess claims, which will differ under each category.

2 Emergency Budget ‘Budget 2010 policy costings’ HM Treasury, June 2010
for work in their work capability assessment despite suffering from serious health conditions and face major barriers to work. Bureaux have reported a worrying trend where clients who win their appeal [to have the decision that they are fit to work overturned] are quickly given a new assessment and found fit for work again or are repeatedly re-assessed. This puts people whose health is already frail at risk of deteriorating (a clear breach of the right to rehabilitation contained in Article 26), and could potentially also affect the levels of care support provision that people receive due to the impact the change may have on their DLA (PIP) and Local Authority funded support.

15 Other concerns raised amongst people with a disability about the work capability assessments surround the inherent ambiguity in how the DWP monitors, and cost-recovers from, the companies when decisions are successfully appealed by claimants. There are concerns that this will carry over to the management of DLA/PIP assessments. They further feel disadvantaged by the government on this, when they stand to lose income themselves. Related to this is the targets system that assessors will use for PIP, which, for the work capability assessments, have resulted in far more people being removed from incapacity benefits than the government predicted (69% as opposed to a projected 49%). As many as one in five working age recipients of DLA in Scotland may stand to lose their benefits when the new assessments take place. The high numbers of people moving off Incapacity Benefit through current work capability assessments include mistakes reflected in the high rates (40% UK wide and up to 70% in Scotland) of successful appeals.

16 Care charges (falling under the Scottish and Local Governments’ remits) reduce disabled people’s available income particularly when they enter employment. The guidance available to local authorities in England allows disabled people to retain more of their earnings when care charges are being assessed. The current care charging guidance in Scotland, taken together with the recent cuts to the Independent Living Fund (ILF), have reduced the income of some disabled people in employment to below Income Support levels (after housing costs, travel to work, etc. are taken into account) (Articles 5, 19 and 28).

17 Disabled people are and will be disproportionately affected by the cuts labelled as ‘welfare reform’, both in terms of their income and the services they receive. Taken in sum, such “regressive government policies seriously undermine the rights of disabled people and the UN [Convention]”.

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Two rates of award

Setting the rate thresholds

18 We notice with some concern that the draft criteria have been written without any statement of the thresholds that will determine which rates a person will be awarded.

19 Many respondents to the consultation expressed fear and concern over the possible withdrawal of the mobility component due to tightening of the criteria, and refer to the ability to use the mobility component to fund a Motability car as their main means to independence. It is often people who currently sit in the middle of the scoring in the new criteria for certain activities who will benefit most from the benefits DLA and PIP bring.

20 Without seeing what thresholds are needed to be awarded the different rates of the benefit it is impossible for us to comment fully on whether these criteria are suitable or not, but we call upon the Government to ensure that, when placing these thresholds, all people who need this benefit are protected. Whilst the simplification of the benefit could, in theory, make it easier to administer, the reduction in the number of components, particularly in the ‘Care’ component, will potentially stop a lot of people who currently benefit from and need the lower rate of DLA from receiving it. The risk is that it will make it less equal and that some people will get a high rate of benefit while other vulnerable, disabled people get nothing. The proposed changes will result in the new benefit being less appropriate to each individual and will result in fewer people being entitled to the benefit.

21 There are concerns regarding the current “main meal” assessment as this is one of the main criteria for awarding benefit and does not accurately reflect the support people with an ABI require to enable them to carry out this everyday activity. Help with planning a meal, supported travel to purchase food and food preparation all require a high level of support. Assessing only the ability to cook a meal does not reflect the high level of support needed to complete this task and is a crude judgement of people’s abilities.

22 Due to the many cognitive impairments that most people with an ABI have, we would suggest that it will be a huge struggle for many people who are unable to process and retain information, to complete the application form without requiring assistance.

23 The application process for DLA is a standard application form and does not provide the scope for people with an ABI to provide information on the level of disability they have. There is also no opportunity to provide information on cognitive deficits - the most common consequence of having a brain injury. It is appreciated that it is unrealistic to have an application form which reflects the full range of medical conditions and/or disabilities; therefore there is a reliance on the
assessment process, which many people perceive as being inconsistent, unfair and very often inaccurate.

24 The main reason for lack of understanding of DLA is the inconsistency in the current assessment and award process. There is a strong view that the assessment panels do not have the level of expertise required to assess the complexities of ABI. Also, many people feel that the GPs used to carry out these assessments do not have the required level of knowledge or expertise to make appropriate assessments. This inconsistency impacts on people’s ability to understand the application process rather than the problem being with completing the application form. As such, we would strongly recommend that a neurologist, neuropsychologist or neuropsychiatrist should be a member of any assessment panel involving a claimant with an ABI, in order that an accurate, competent and safe assessment can be made.

25 Having two different levels of award for each component part of the benefit does recognise that people with certain conditions will have varying degrees of similar needs and the amount of benefit should reflect this. Again, unless there is a clearer and consistent assessment, appeal and award process, there will continue to be confusion and lack of public confidence in the process of allocating DLA and the new Personal Independence Payments.

26 By removing one level of award as with the current system, some people with disabilities will lose benefits, which will have a massive impact on their quality of life and their ability to play an active role in their community. As the form very much focuses on the physical aspects of disability (which as already mentioned, not everyone with ABI will have), many people with cognitive problems that affect their ability to get around and participate in society will go unrecognised. We would suggest that it could also be potentially harder for those currently on the low or middle rates to get the benefit at all, which would result in even greater financial hardship for this particular group of disabled people and their carers.

27 People who already claim the lower rates of DLA are awarded the benefit on the basis of need – this need will not go away simply because the lower rate has been withdrawn, but it seems, will simply be ignored.

**Automatic entitlement and indefinite awards**

28 We think it would be fair to assess each claim on the basis of need, as long as the assessments are carried out equitably by professionals with the relevant clinical expertise in the condition concerned. If someone has an obvious condition which is regarded as a long term condition and the prognosis for that condition is that it will not improve with time, then we would suggest that reassessment is clearly not necessary.
Additional comments from our service user panel

29 What can improve in the longer term is how people with these conditions learn to cope with their disabilities, and DLA has been instrumental in improving people’s quality of life by allowing them to have the financial freedom to lead a more independent life. People who have sustained an ABI will not always be able to regain certain brain functions; therefore the cognitive and mobility deficits will not be regained through time. People with an ABI will also require ongoing support both from a physical, emotional and psychological perspective with their disability being life-long condition. As such, there should be automatic entitlement to DLA and the new Personal Independence Payment. As already mentioned throughout this document, an ABI has a massive impact on energy levels, ability to concentrate, anxiety, memory, planning functions etc, all of which are “hidden” impairments that are difficult to demonstrate on the current forms. If an individual’s brain injury is severe and there is little chance of further improvement, there should be no requirement to have continual assessments and reviews, which cause undue stress and anxiety for people with long term medical conditions, their families and carers. Repeated, unnecessary assessments also incur an additional higher financial cost to the DWP which is money that could be saved and used far more efficiently and effectively.

Qualifying period

30 We believe that the length of time from application to securing DLA payment is unacceptable. The proposal to have a six months qualifying condition does not reflect the fact that some medical conditions have an instant impact on people’s ability to (return to) work and function normally. For some conditions such as ABI the medical prognosis is straightforward and depending on the severity, these conditions should not have to meet the six months qualifying period. The length of qualifying period also causes undue financial pressures for carers and families and makes life even more of a struggle, exacerbating the impact of the ABI. This additional financial pressure can often lead to further anxiety, debts, family break-ups and mental health issues.

31 The impact of a 6-month qualifying period also has a huge impact upon many family members who instantly become carers following a trauma. Many have to give up work to assume a caring role and therefore the financial burden is immediate.

Passporting

32 It is essential that the new PIP retains the passporting that benefits so many DLA claimants today. Schemes such as disabled travel cards and Motability are key reason why many disabled people are active members of society, and withdrawing these services would condemn thousands of people to a life of poverty and reliance on social care services.
33 There is an inconsistency in allocating bus passes, and only those who qualified for the middle and higher components receive bus passes. For those people with a disability who can access public transport, the travel card has huge benefits, and assists people to get out and about at a reduced cost. For others who have used their mobility component to fund a car, this has greatly increased their independence to get about and remain more active. It would useful to review the issue of travel cards with the introduction of the new benefit; as part of the assessment process it should be established if applicants are able to use public transport and would wish to access a travel card. This would lead to greater social inclusion and opportunities for increased independence.

34 DLA and the new PIP should be a passport for free prescriptions and eye care as currently only those people on income support receive free prescriptions and eye care. DLA and the new PIP is a benefit which recognises that people have a medical condition yet those who live outside Scotland are required to pay for their own prescriptions and eye care.

35 Many people with a long-term condition will require to take medication for long periods of time and the cost of their medication can often be a financial burden. Given the fact that DLA is a benefit based on people’s medical needs, is it not appropriate that they also receive free prescriptions and eye care? ABI is a condition which can very often require people to take various types of medication for life; some people who have sustained ABI also have problems with their vision which will require ongoing medical treatment and support. Given that ABI results in restricted mobility and also can have an impact on core body temperature particularly if the pituitary gland has been damaged, it would also seem appropriate that people in receipt of DLA or PIP are automatically entitled to the winter fuel allowance.

**PIP assessments and delivery**

**The independent assessors**

36 As already mentioned we are extremely concerned about the lack of expertise of the assessors for PIP. We would like to see only clinicians and medical staff with specialist knowledge of acquired brain injury assessing people in this group. We are certain that many medical professionals, such as General Practitioner’s, have very little or absolutely no knowledge whatsoever of this complex condition, and of the cognitive, psychological and behavioural effects, which are often not visible.

37 It is also vital that the opinions and statements from treating medical professionals and/or family members are taken into account, as in the case of ABI in particular, many people lack insight into their own condition. This will make them unable to answer questions accurately, resulting in a high risk of an inappropriate award being made. In all cases we would recommend that the person being
assessed is urged to bring a carer, family member, and friend or advocate who can assist in the assessment process.

38 We are also extremely concerned about the level of independence of the assessors, and whether they will be given targets for rejecting claimants given the proposed 20% reduction in claims.

**Assessing brain injury accurately**

39 While we welcome the addition of a number of criteria that take cognitive deficits into account, we feel this should go further to take account of the many behavioural and psychological effects of brain injury, plus the more complex cognitive problems people experience.

40 Fatigue is one of the most debilitating yet hidden effects of brain injury, and yet there is no mention of this in the draft criteria. As an example, given the varying picture this symptom creates, an assessor could visit a claimant in the morning and make a judgment based on their ability at this time, unaware of the serious impact that fatigue levels later in the day could have on their performance.

41 This applies to the common symptoms of poor motivation and lack of insight too, so for example a person might be able perform a task, but would have no motivation to do it, or insight into why they should. How will the Government ensure that this is taken into account in order to protect the most vulnerable people in our society?

42 While we appreciate that many symptoms of brain injury are taken into account much more than with DLA, we still feel the criteria will leave large gaps in the full assessment of disability. For example, greater emphasis is needed on the effects of communication problems caused by cognitive functional deficits, and also the complex and wide ranging memory problems that result from a brain injury.

43 We can see a large gap in the criteria where the basic activities of daily living are not being assessed. This includes sleeping, breathing, relationships and sexuality, none of which are being considered anywhere in the proposals.

44 There is also an important category missing from the criteria – an individual’s ability to maintain positive physical and mental health. This needs to take account of their ability to use services such as dentistry, opticians, chiropodists, counselling and local community mental health/acquired brain injury teams.

45 It is also important that the Government is sensitive to the stress that a benefits assessment can place on claimants; particularly in the case of brain injury where focusing on the negative aspects of a trauma can have serious psychological consequences, possibly leading to exacerbation of symptoms and/or additional behavioural problems.
Safeguarding

46 We do not feel that the safeguarding agenda is implicit throughout the activities to be assessed. While the benefit assesses a claimant’s ability to perform basic everyday tasks, it makes no mention of their ability to protect themselves against all forms of exploitation, for instance from financial, physical, psychological and sexual abuse.

DLA/PIP – children and adults over the state pension age

47 Headway provides support to adults with an acquired brain injury and therefore do not have the level of expertise or knowledge to respond to the question regarding children.

48 We would however comment on the proposal for people over state pension age and argue that age should not be a factor in the PIP assessment process. Acquired brain injury has a devastating effect and access to disability benefits should not be discriminatory.

Communicating the reform proposals

49 People who are currently in receipt of DLA will have an understanding of the eligibility of the new benefit and prior to the introduction of Personal Independence Payment they should be advised of the changes in the assessment process and levels of award. Benefits advice should be available in GP surgeries, hospitals and social services departments, especially when people have sustained an injury which is likely to leave them unable to return to work, or if an injury will result in the person requiring ongoing support and care. Hospital Social Workers, where accessible, should also be able to signpost people onto benefits advice if they themselves are not able to provide it. Benefits advice and support should also be included in hospital discharge plans, if the person has sustained an injury which will result in a long term medical condition such as an ABI. There should be clear referral processes established in neurological wards of hospitals, as these patients are the most likely to be unable to work and will have to rely on DLA (PIP). Patients, and more often than not, carers, should be given contact details of independent benefit advisors in their local area. One suggestion which would also assist this process would be to hold benefit surgeries periodically within these specialist hospitals.

50 The difficulty in providing information as to who is likely to get the benefit results from the inconsistencies in awards.

51 All benefit information must be written in plain English language, with clear information about what the qualifying conditions are and identifying the components parts to the benefit, and the levels of award. Definitions of mobility and care should also be given in the information with examples provided.
52 Better training for the people who administer the benefits on what’s available and on different conditions (as well as where to access expertise and advice on specific conditions). TV advertising, information left in hospitals, CAB, community projects (Third Sector organisations), libraries etc.

**Transitional arrangements**

53 We would propose that people who are currently in receipt of DLA should have their case reviewed without the need to attend a re-assessment. The review should focus on whether or not the condition is recognised as a long term (disabling) condition and unlikely to result in significant improvements. Expert advice should be sought from medical professionals i.e. neurologists, on the likelihood of there having been major changes to peoples level of disability and we would recommend that as an ABI is recognised as a long term condition then these claimants should automatically be transferred to PIP.

54 New claimants should go through the assessment process to establish if they have a recognised long term condition, and, if so, then a paper based assessment should be completed. For claimants who have a fluctuating medical condition an assessment might be appropriate, but only to ensure that a fair award is given based on their ‘worst day’.

**The tendering of DLA/PIP assessment contracts**

55 We would recommend that the assessment contract include a penalty clause for flawed assessments. There is a volume of evidence* which identifies that at least 80% of claimants, who have been wrongly assessed as fit to work, win on appeal.

56 Currently ATOS are paid for what can only be viewed as “flawed or incorrect” assessments which incur additional costs, as these cases are then referred to an independent appeal panel. Given that the replacement for Disability Living Allowance (PIP) aims to cut the amount of PIP paid to working age adults by 20%, it is our view that if 80% of assessments are flawed, the introduction of penalty clauses would assist in improving accuracy whilst decreasing unnecessary costs. The other alternative would be to withhold or remove payment for flawed assessments, and these savings then going towards assisting the Government in meeting the budget deficit, rather than cutting the payment of PIP to disabled people.

57 From our consultation on this issue, we know that public confidence in the current and proposed assessment process is extremely low and is in the main due to the high number of claims which are referred to the appeal panel, and as previously mentioned 80% of these cases will be upheld.

Applying the above suggestions would result in the reduction in the number of flawed assessments, whilst also greatly reducing the number of appeals required, and this in turn would go some way to restoring public confidence in the assessment process. If the assessment process resulted in more accurate awards this would also greatly reduce the level of stress and worry that claimants and their carers have to face.

**Conclusion**

In assessing the draft criteria, many of our service users who currently claim DLA felt that reducing the assessment to just a few tasks left out many of the essential daily activities that they are unable to perform.

A stated principle of PIP was the process being more active and enabling, however this does not seem to be the case within the proposed assessment criteria itself. Headway does not feel confident that the numerous cognitive, emotional, psychological and behavioural effects of brain injury are being taken into account across the 11 proposed activities. For example they do not take account of problem solving, fatigue, memory problems, comprehension and cognition, anger, sexual problems, sleep disorders and safeguarding issues.

Headway service users involved in this consultation spoke about the growing stress and fear of the unknown and the thought that genuine cases will lose out. Respondents also felt that their input will not play a significant part in influencing the draft assessment criteria consultation, something which clearly shows the lack of confidence in the whole process. We would be particularly interested to learn how the Government will judge the success of this new benefit, and under what criteria it will be judged against?

We believe that if the Government is to achieve its aim of producing a fairer benefit to help vulnerable people access greater independence, it is vital that, the issues raised within this consultation response are taken fully into account.
Question 1

Have you noticed changes to the WCA process as a result of the Year 1 recommendations? If so, what are these changes?

A. Process has improved
B. Process has broadly stayed the same
C. Process has got worse
D. Not noticed / not sure

Answer

t (delete as appropriate) and provide any written comments …

The waiting time for assessment has worsened since the recommendations were put in place. This could be as a result of more people having to undergo face-to-face assessments, rather than paper-based evidence, which obviously take longer.

The assessment appointments can run substantially over time and people turning up on the day for their assessment can be offered another appointment, given the length of waiting times on the day. People are also being telephoned on the day of their assessment to be advised that other appointments have over-run, so their assessment has been cancelled and will be rearranged for some time in the future. This causes huge difficulties for applicants and results in undue levels of distress and anxiety.

The fact that some assessment are carried out by people with limited medical experience, whilst others are referred to participating GPs, leads to an inequality and inequity of the assessment process. The number of decisions made by the assessment process that are overturned on appeal (80% of appeals1) demonstrates that the assessment process is fundamentally flawed and continues to be so.

There is also a perception that people are being subjected to far more frequent assessments than in the past and this leads to a huge increase in levels of stress and anxiety, which can have a detrimental effect on those for whom stress and anxiety are symptoms of their medical conditions.

1 P3, Citizens 2011 Advice Scotland (Scottish Association of Citizens Advice Bureaux) (2011)
2 Snapshot: Advice Trends in Scotland Jan-Mar 2011

Question 2

Are there further areas of work that you think should be added to the programme of work for Year 3? If so, what should these consider?
A. Major areas of work required
B. Minor areas of work required
C. No more areas of work required
D. Don’t know

Answer
A (delete as appropriate) and provide any written comments …

The programme of work should include additional efforts to examine the assessment process. There are still a significant number of cases which go to appeal, and are won. This is costly and time consuming and also indicates that the assessment process continues to be severely flawed. The introduction of specialist medical professionals for specific and complex medical conditions would help to ensure that the assessment process is more accurate, and that the person carrying out the assessment has sufficient medical knowledge and understanding of the condition being assessed. This could assist greatly in reducing the number of cases referred to appeal which would result in reducing the costs associated with the assessment process.

Question 3

At what stage should we stop making changes to the system and let the changes already being made bed in to ensure they are having the desired impact?

A. Don’t stop making changes until the process is considered theoretically perfect
B. A few more changes are needed, but then pause to see their impact
C. After Year 2 changes it will be time to assess what impact changes to date have had before making more
D. Don’t know

Answer
A (delete as appropriate) and provide any written comments …

It would be wrong to stop making changes if the process continues to be flawed. Failing to continue a review and change of the assessment process will lead to more clients being wrongly assessed and more vulnerable people losing out on this vital benefit.

Also, if it were not possible to continue to review the process then clients who were perfectly entitled to claim ESA but had lost out due to the flawed nature of the process would continue to be unable to claim benefits. The number of appeals and the reason for upholding appeals should be reviewed to evaluate if there is a trend in the types of medical conditions which continue to be wrongly assessed.
Question 4

Does the Year 1 recommendation go far enough in placing the right emphasis on the face-to-face assessment?

A. Does not go far enough – still too much emphasis on the face-to-face assessment
B. Balance between the face-to-face assessment and the rest of the process now about right
C. Goes too far – now too little emphasis on the face-to-face assessment
D. Don’t know

Answer
A (delete as appropriate) and provide any written comments …

There is still too much emphasis on face-to-face assessments and, until such time as there is specialist medical advice made available during the assessment process, clients will continue to be wrongly assessed.

For those medical conditions which are long term and the effects of which are well evidenced and researched, the need to have face-to-face interviews should be limited, whereas for fluctuating conditions a proper specialist assessment should be made. The cost of having unnecessary face-to-face interviews with people who have long-term debilitating conditions could be reduced and reducing these costs this could assist the Government in meeting the 20% budget target.

Question 5

Do you have any robust evidence about the face-to-face assessment processes and outcomes which will help us make recommendations for future improvements?

Answer
Please provide any written comments …

Many Headway service users have contacted us to share their concerns and frustration with the WCA. The process has caused a great deal of anxiety, with a number of reports of the assessment, report and subsequent decision taking very little account of the true nature of their complex disability.

The evidence provided by the Citizens Advice Bureau stating that 80% of cases are upheld at the appeal stage demonstrates that the assessment process continues to be flawed to such a degree that it verges on being an unsafe process. Evidence from the CAB should be further investigated to establish if there are trends in the medical conditions being wrongly assessed so that independent medical expertise can be sought for the more complex medical conditions. It could very well be that hidden
disabilities, such as brain injury, represent a significant proportion of the cases which are assessed incorrectly due to lack of knowledge, skills or expertise.

Referring to the BSRM *Vocational assessment and rehabilitation after acquired brain injury*\(^2\) guidelines (paragraph 8.11), “As part of the vocational and/or employment assessment, the DEA, Jobcentre Plus work psychologist, independent practitioner or Work Preparation provider should be provided with copies of relevant clinical reports and/or liaise directly with the neuropsychologist and/or occupational therapist ... to obtain a full understanding of the effects of the brain injury”.

Given this very established and expert opinion, which was produced in cooperation between experienced physicians, rehabilitation professionals and the JobCentre Plus, how can the DWP justify there being no specialist input in the WCA in the case of a complex condition such as brain injury?

\(^2\) *Vocational assessment and rehabilitation after acquired brain injury*, Inter-agency guidelines, BSRM/JobCentre Plus/Royal College of Physicians, 2004

**Question 6**

**Are you aware of any concerns about the face-to-face assessment, and if so where have these been focused?**

A. HCPs approach and the way they carry out assessments  
B. HCPs understanding of conditions  
C. The report created during the assessment and the IT supporting the assessment  
D. All three of these  
E. Don’t know

**Answer**  
D (delete as appropriate) and provide any written comments …

All three of these options reflect the concerns of disabled applicants. The assessment process does not reflect the person-centred agenda and, in our opinion and experience, the assessor’s attention is mainly focussed on completing the tick-box computer-based assessment programme rather than focussing on the person being assessed and their capacity to answer standardised questions. The opportunities for applicants to provide detailed and personal information on the consequences of their medical condition are limited as the assessment programme has very set, rigid questions, which for complex conditions like acquired brain injury (ABI) do not reflect the many cognitive, psychological, emotional and behavioural deficits which occur.

In general, the assessors do not have appropriate levels of medical expertise required to assess the more complex medical conditions and are therefore not able to prompt or “dig deeper” into the disabilities people have as a result of their medical
conditions. Many people who have an ABI lack insight into their disabilities and it is only with prompting and having a level of knowledge and understanding of their conditions that a true reflection of the cognitive difficulties can be identified and recognised.

There are also cases reported by Headway service users where medical evidence has been presented to the assessor and this has been disregarded and not taken into account during the process. There are also inconsistencies in how the assessment is carried out, with some applicants having access to a GP and others being limited to less qualified medical staff. This can lead to inequalities and discrimination in an already unfair process.

The report created by the assessor is extremely long and is difficult to interrupt. The report is based on the assessor’s understanding and interpretation of the applicant’s responses and, given that many of the assessors lack the medical expertise required to carry out safe and robust assessments, these reports can very often fail to accurately reflect the conditions being assessed. Many Headway service users have commented that the reports produced are viewed by applicants as not reflecting their specific conditions in any detail. The reports demonstrate the standard nature of the assessment programme and their inflexible, ‘tick box’ approach.

Question 7

If you have heard specific concerns about the IT supporting the assessment (i.e. the Logic Integrated Medical Assessment or LiMA system), do you have any robust evidence about how this adversely affects the assessment or its outcome?

Answer

Please provide any written comments …

The IT assessment is highly standardised and limits the face-to-face opportunities with suitably qualified medical professionals to extrapolate detailed information from applicants on the debilitating nature of their medical condition. Many applicants refer to the assessment being merely a tick-box exercise with very limited opportunities to record complex conditions. The high level of cases which are referred to appeal panels with assessment decisions being overturned should provide enough evidence in itself to demonstrate that the assessment process remains fundamentally flawed. Further examination of these cases should be undertaken to establish the flaws in the process and what types of disabilities are being wrongly assessed or missed.
Question 8

**Is there a need to present and explain the face-to-face assessment in a different way, making it very clear to claimants what it will involve and how a functional assessment relates to work capability?**

A. Urgent need to present and explain the face-to-face assessment in a different way
B. A need to present and explain the face-to-face assessment in a different way
C. Not sure whether there’s a need to present and explain the face-to-face assessment in a different way
D. No need to present and explain the face-to-face assessment in a different way
E. Definitely no need to present and explain the face-to-face assessment in a different way

**Answer**
A (delete as appropriate) and provide any written comments …

There is an urgent need to present and explain the assessment process alongside a review of the process in its totality. The high number of cases which are won on appeal clearly demonstrates the process continues to be flawed to such an extent that 80% of cases win their appeals.

The proposal to present and explain the assessment process will not result in safer, more robust assessments until the assessment process itself is reviewed, the flaws identified, and improvements are made. There continue to be inconsistencies in assessments and the provision of information in itself will not bring about a reduction in the number of flawed assessments.

Question 9

**What one thing would you change about the WCA to make it operate more fairly and effectively?**

**Answer**
Please provide any written comments …

The assessment process has to be reviewed and overhauled. Expert, specialist advice must be available to assessors for the more complex conditions so that these conditions can be assessed in a robust, consistent and safe way. If the assessment process is reviewed and overhauled this will result in the reduction in not only the number of appeals being made, but also in the number of appeals being upheld. This
will provide the evidence required to indicate a sound, safe and robust assessment process.