Dear Professor Harrington

Submission into the Harrington Review on the Work Capability Assessment

First, I would like to apologise for the lateness of this submission into your second review of the Work Capability Assessment.

Around 150,000 people every year have a stroke in the UK and around a third of these people are left with a disability. Therefore The Stroke Association is concerned about the amount of negative feedback we currently hear about the Work Capability Assessment.

For example, we recently heard from one stroke survivor who undertook the Work Capability Assessment and was deemed fit to work but then appealed successfully against the decision. He said that he found the appeal ‘humiliating and degrading’, had ‘been called a liar’ on numerous occasions by professionals. He also told us that the process was ‘extremely stressful,’ and once he was made aware of the process of appeal he felt ‘very down and very low’ and ‘demoralized’. He experienced anxiety and suffered loss of sleep which contributed to his exhaustion. He told us that ‘the stress sapped my energy and I felt constant fatigue’.

Unfortunately this is not an unusual experience and we know that it is in everybody’s interest that the assessments are accurate and fair to minimise stress and save money.

These concerns led us to wanting to find out more about how the assessment is carried out and what guidelines are used by the assessors. We were recently sent the DWP/ATOS medical protocol for stroke which was passed on to us by the Disability Benefits Consortium. We then passed this on to two of the most respected experts in stroke care in the UK, Professor Marion Walker and Dr Tony Rudd who are also trustees of The Stroke Association.
Professor Marion Walker is a professor in Stroke Rehabilitation and the Associate Director UK Stroke Research Network. She told us:

“It worries me that this is the guidance that is used for work capability assessments. The overview of rehab is scant to say the least. There is very little on the hidden deficits after stroke – fatigue, loss of confidence, perceptual and cognitive problems etc etc. These are the issues that really prevent stroke survivors from returning to work. The other worrying thing is the reference to potential for recovery. We know most stroke survivors don’t return to work until around a year post stroke. And because employers are not in tune with stroke problems … work retention is a very major problem.”

Dr Tony Rudd is a Consultant Physician in Stroke and he had a number of comments on the protocol.

Firstly, he has questioned the validity of a number of statements in the protocol. For example

- “Onset [of stroke] during sleep or on rising may suggest infarction while onset during exertion may suggest haemorrhage but this is not reliable for diagnosis.”
- “In some cases infarcted tissue has to become fluid before it can be visualised and this can take some days.”
- “Complete recovery is uncommon but the sooner improvement begins the better the prognosis.”

These statements are all untrue according to Dr Rudd and he also found the whole section on the main disabling effects of stroke to be strange to say the least.

Dr Rudd also reported that some of the statements are too definite. For example to say that “any deficit remaining after 6 months is likely to be permanent” is not true as, with the right rehabilitation and support, improvements can still be made after the first six months. It is also untrue to say that “about half of all recovery from this disability occurs over the first month and can continue for six months.” Whilst rehabilitation and support are more focused in the early period post stroke this rarely lasts up to six months. However it is hard to measure improvement and it varies from individual to individual. Therefore the WCA needs to be accurate and flexible in order to take in the needs of the individual. Stroke survivors are supposed to receive an initial six month and then annual post stroke assessments from medical experts in stroke. Any future protocol should ensure that the WCAs take these post stroke assessments into account when making the decision on Employment Support Allowance.
Also, he told us that it is not necessarily true that “during the first days of an ischaemic stroke neither the progression nor outcome can be predicted”.

In light of these concerns over the protocol we hope that your review decides to firstly update the current Stroke Protocol and that these protocols are regularly reviewed in line with current best practice. At The Stroke Association we would be more than happy to advise the Department for Work and Pensions to ensure that the Stroke Protocol is accurate and allows the assessment to be fair.

Yours sincerely

Joe Korner

Director of Communications
Stroke Association position paper on welfare reform

September 2011

Summary
Stroke is the leading cause of adult disability in the UK and around one third of the 150,000 people who have a stroke every year end up experiencing some sort of disability. Furthermore around a quarter of all strokes happen to people of working age. These statistics are the reason why The Stroke Association is deeply concerned about some of the changes that are either being implemented already or are being proposed by this government.

The Stroke Association welcomes some of the rationale for the government’s reform of welfare. It is clear that the system of benefits is highly complex and needs to be simplified. We also support the need to provide more opportunities for those people, who can, to be able to work.

However, stroke survivors and carers have told us that they are very concerned, frustrated and confused with regards to these reforms. Many are in fear of how they will cope with the removal of, or cuts to, their benefits.

The Stroke Association is calling for a welfare system that:

- Does not place anyone who has had a stroke or their immediate family into financial hardship
- Does not overly burden stroke survivors or their families with the need to undergo multiple assessments
- Is clear and comprehensible and does not confuse applicants at a time of major stress and difficulty
- Encourages those stroke survivors and carers who can work, to work
- Takes into account the specific needs of stroke survivors and their carers including the fact that stroke is a fluctuating condition.

Financial hardship
Reduction of the annual welfare budget is clearly one of the reasons for the current changes. According to government figures:

- Changing Incapacity Benefit to Employment and Support Allowance (ESA) is to save £1 billion
- Replacing Disability Living Allowance (DLA) with Personalised Independence Payment (PIP) (in 2013/14) aims to save over £2 billion
- Introducing Universal Credit (in 2013/14) will save £7 billion.

However, The Stroke Association would have great concerns if this drive to save money resulted in stroke survivors and their families being placed in even further financial hardship by these changes. Our evidence shows that almost one in five stroke survivors experience a loss in income after their stroke and reducing benefits will place already vulnerable people in an impossible situation.
Around 110,000 stroke survivors currently receive DLA and the change from DLA to PIP raises a number of issues. According to government figures 110,000 claimants of DLA are stroke related. Under PIP, stroke survivors would only be allowed to claim six months after their stroke.

*Bearing in mind that stroke survivors particularly those who will have been working will still need to pay a mortgage, support their family etc, what financial help will be available to stroke survivors in the first six months after their stroke?*

In terms of the time limiting of contributions based ESA, our concerns are that this change will have a particular negative effect on stroke survivors who have worked and paid into the system for their whole working life. Someone who has worked since they were 18 could have been paying National Insurance for 40 years and at the age of 58, has a stroke. They may only then receive one year of ESA and if their savings or partners income is over a certain amount, they will not receive any ESA after a year. The impact of stroke is already stressful and family problems could be exacerbated by this change.

The removal of the mobility component from the DLA (and future PIP) is very concerning to us and many other charities. So far we have successfully campaigned to get the government to review this decision and delay implementation until March 2013. However, if it still goes ahead, many stroke survivors could experience a worse quality of life and be stranded within their care home. Out of the 110,000 claimants of DLA who are stroke related, over 87,000 receive the higher rate of the mobility component. Should this be taken away they will be left with just the £22 per week Personal Expenses Allowance (PEA). This is not intended to cover additional mobility costs. It is intended to cover personal costs such as clothes, toiletries and phone bills. Without the DLA mobility component, the PEA is not enough to cover additional mobility costs and people will be left without the money to meet basic mobility needs. We are particularly concerned that stroke survivors in care homes will no longer be able to attend the communication support groups we run without the mobility component of DLA.

*In the government’s review of this decision, have they listened to stroke survivors who live in state funded residential homes?*

In terms of the Universal Credit (UC), we support other welfare rights groups which believe that the Government should only implement this when the supporting systems have been built tested and proved fit for purpose.

*Has the government listened to concerns over UC and will they include stroke survivors in any future testing?*

*Overall has the government carried out an impact assessment into how these changes will financially affect those claimants of benefits who are categorised as ‘stroke related’?*
The assessment phase
The after effects of stroke can be complex and vary from one person to the next. This includes physical, communication and neurological issues. Stroke survivors have told us that in order to be successful, a benefits application and assessment system must account:

- for the difference in effects of stroke from person to person
- for it being a less visible disability
- for stroke as a fluctuating condition
- for a lack of government and professional understanding of stroke

We share the concerns of many other charities and the Disability Alliance around the Work Capability Assessment for Employment Support Allowance. Evidence appears to suggest that people with serious health conditions are frequently declared fit for work. In fact a freedom of information request in 2009 revealed that of the 600 stroke survivors who challenged the decisions in tribunals, 55% had the assessor’s decision overturned.

We are aware that the government have asked Professor Harrington to carry out a second review into the WCA and we would urge this review to take account of the needs of stroke survivors.

The Stroke Association notes that the latest information we have is that the Personal Independence Payment will use face to face interviews for the assessment rather than a form. Whilst we support the move away from complex self assessment forms, we would like assurance that the face to face interviews will take account of communication difficulties such as aphasia?

**Can the government give us an assurance that stroke survivors needs will be taken account of in the designing of the PIP assessment?**

It should be obvious that the months after having a stroke can be a very stressful period as well as a physical difficult time. Apart from the financial pressures which could exacerbate these problems (outlined above), we are concerned that there could be a large amount of assessments for stroke survivors. Will some stroke survivors fall into a category of people having to be assessed for PIP, ESA and UC?

**Therefore are the government able to confirm how many potential assessments a new stroke survivor could be required to undergo?**

**Getting back to work**
Around one quarter of strokes happen to people of working age. Therefore, many of them are keen to get back to work after they have recovered. We would support any measures which assist stroke survivors to return to work when they are ready.

However, we would be strongly against any measures which forces stroke survivors into work before they are ready.
What support will be put into place so that those stroke survivors and carers who can work, will be able to?

What checks will be placed in the system to ensure that stroke survivors are not forced into work unrealistically?

Assistance to navigate the system
As stated previously, the months post stroke can be a stressful and anxious time for both the stroke survivor and their family. We would be greatly concerned if anyone’s recovery from stroke is put at risk from stress and anxiety.

The last thing these families need is to become overwhelmed with the benefits system. Some of the issues expressed to us around this issue are:

- The system is too complex with too much confusing jargon
- There is too much variation in types of support and lack of explanation/advice
- The forms are difficult for people with cognitive problems

Whilst we support the government’s aim to simplify the system it is clear that the current changes are a massive overhaul of the system. Furthermore anecdotal evidence from our Independent Advice and Support Coordinators who are commissioned to carry out health and social care work (and not benefits advice) are being overwhelmed with clients who are seeking assistance with benefits due to cuts in local benefits advice services.

We would therefore call on the government to ensure that measures are put into place to increase benefits advice services at a time when they are needed most.

Carers
DLA is a gateway for carers to access benefits and if the number of people on PIP is to be reduced, then families who also receive Carers Allowance will be hit twice as they face losing this as well.

We understand that benefits for carers is a historically complex challenge but we would call on the government to ensure that families who are coming to terms with the affects of stroke are not doubly penalised by the reforms.