

Fluctuating Outcomes: Work Capability Assessment & Mental Health

A Report by The Consultation and Advocacy Promotion Service



This resource has been produced by The Consultation & Advocacy Promotion Service (CAPS)

"Fluctuating Outcomes: Work Capability Assessment & Mental Health" Copyright © 2011

CAPS grants permission to reproduce sections of this work for personal and educational use only, in which case CAPS expects to be fully acknowledged as the author of this work. Commercial publication, copying, hiring or lending is prohibited and constitutes a breach of copyright.

Contact



The Consultation & Advocacy Promotion Service
5 Cadzow Place
Edinburgh EH7 5SN

Phone: 0131 538 7177 Fax: 0131 538 7215

www.capsadvocacy.org contact@capsadvocacy.org

'I feel like I am being punished for having a long-term condition'

- ESA Focus Group Attendee

'You shouldn't have to compromise your dignity to get what you're entitled to'

- CAPS Individual Advocacy Worker

CONTENTS

CONTENTS	4	
WHAT IS CAPS?	5	
WHY PRODUCE THIS REPORT?	6	
PROCESS	7	
ANALYSIS	8	
CURRENT SITUATION	9	
DEFINITIONS	11	
WHAT DID PEOPLE TELL US?	14	
FLEXIBILITY FOR MENTAL HEALTH?		15
FLUCTUATING CONDITIONS?		
THE ASSESSMENT PROCESS		
THE ACTUAL WORK CAPABILITY ASSESSMENT:		
OVERALL ASSESSMENT EXPERIENCE:		
SCORES PLEASE THE POINTS SYSTEM		
APPEALS		
EMPLOYMENT SUPPORT?PROFESSIONAL KNOWLEDGE		
SUPPORTING EVIDENCE		
IMPACT OF THE PROCESS		
INDIVIDUAL ADVOCACY		0
CONCLUSIONS AND NEXT STEPS	30	
ACKNOWLEDGMENTS	31	
APPENDICES	32	
THE CUSTOMER'S JOURNEY		33
REASSESSMENT OF INCAPACITY BENEFITS		34
TIMETABLE OF CHANGES		35
HARRINGTON REVIEW OF THE WORK CAPABILITY ASSESSMENT		
CITIZENS ADVICE'S SURVEY OF MEDICAL REPORTS		
INITIAL FOCUS GROUP		
QUESTIONNAIRE DEVELOPED FROM FOCUS GROUP		47

-

What is CAPS?

CAPS is an independent advocacy organisation for people who use, or have used mental health services.

CAPS works with mental health service users as individuals or as members of a group to set their own agenda, to find a stronger voice, to get their point across, and influence decisions which affect their lives.

CAPS is set up so that the organisation and its advocates are as free as possible from conflicts of interests with the people it supports. CAPS provides collective advocacy in Edinburgh, Midlothian and East Lothian and individual advocacy in Midlothian and East Lothian.

Collective Advocacy is about groups of individuals with a common cause who come together to raise awareness, campaign and influence service planning and provision.

Individual Advocacy is about a person having an advocate to help them express their views and have more influence over decisions being made about their lives.

CAPS does this by:

- developing and supporting user groups;
- encouraging a spirit of partnership between service users and the people who plan, pay for and provide those services;
- publishing service user views on mental health issues;
- involving service users in the development of services;
- making service users aware of new kinds of services and options that are available to them:
- providing advocates to work with individuals;
- recruiting, training and supporting volunteer advocates;
- promoting the principles of independent advocacy.

CAPS is funded by City of Edinburgh, East Lothian & Midlothian Councils, NHS Lothian, and East Lothian Community Health Partnership.

CAPS
independent
advocacy
The Consultation & Advocacy
Promotion Service

CAPS is a Scottish Charity, Number SC021772

Why Produce this Report?

Over the past couple of years there have been some big changes to the benefits system.

One of the biggest changes has been the introduction of Employment Support Allowance (ESA). Everyone who applies for ESA has to go through a Work Capability Assessment (WCA) to decide whether they can do some type of work.

CAPS met with a group of people who have had experience of the WCA and gathered their views on how they feel the system is working. After this initial focus group, we developed a questionnaire to find out more about how the process is affecting people with mental health issues. The aim of this research is to gather relevant information so we can inform relevant authorities about how the system is working or if it needs to change.

Process

Service users about to go through the ESA process and people having gone through the Work Capability Assessment contacted CAPS to express their concerns about how the process affects people with mental health issues.

On 3 November 2010, a Lothian-wide focus group was organised to gather the main issues and decide on a course of action.

Fifteen people attended and the focus group discussed the most important issues around ESA needing urgent attention.

CAPS produced a questionnaire around people's experience of the assessment.

The questionnaire was sent to a wide range of voluntary organisations and individuals in the Lothians. It was also advertised via social media and an online version was available on Survey Monkey.

CAPS researched other initiatives around ESA and mental health, and looked at the wider context and reviews.

CAPS collective advocacy linked up with their individual advocacy service to gage the impact of the assessment on individual advocacy services.

The twenty surveys sent back by mental health service users in Edinburgh, East Lothian and Midlothian were collated and analysed.

Analysis

A questionnaire about both people's experiences and concerns related to Employment and Support Allowance and especially the Work Capability Assessment was developed following a focus group run by CAPS. Members of the focus group reviewed the questionnaire before it was circulated.

The questions were developed based on the main themes which came out of the focus group and were agreed to be the main areas of concern.

The questions focused on both the structure of the ESA process and the WCA. The full questionnaire is included as an appendix at the back of this report.

Current Situation

What are the changes and when are they taking place?

Since October 2010 and until 2014, people who receive Incapacity Benefit (IB), Severe Disablement Allowance (SDA) and Income Support (IS) paid on the grounds of illness or disability are being re-assessed for Employment Support Allowance (ESA).

Those assessed fully capable of working are invited to make a claim for Jobseeker's Allowance (JSA), are able to claim Income Support or have to move off benefit. Those who cannot work or have limited capability to work get to move to ESA.

How does this affect people?

All people currently in receipt of incapacity benefits customers will have their claims reassessed by 2014. Most people undergo a Work Capability Assessment to determine their future benefit entitlement. The assessment concentrates on what people can do rather than what they can't. People will continue to receive their current benefit until a decision is made.

Why is the Department of Work and Pensions reassessing incapacity benefit?

They want to phase out some benefits as they think it makes no sense to have several different benefits for people with health conditions.

They also think that many people, with the right support, could and do want to work but the current system doesn't give them that option. They say there is growing evidence that work can promote recovery from both mental and physical health problems and minimise the risk of the physical, mental and social effects of long-term unemployment such as social exclusion and poverty.

When a decision has been made:

Where a person is assessed as eligible for ESA, their claim gets transferred automatically. The Department of Work and Pensions wants to ensure that benefit payments are not disrupted.

There are two groups in ESA, with different allowances and conditions:

1. Work-Related Activity Group

People who could realistically go back to work will be placed in the ESA Work-Related Activity group. They will be expected to take part in work focused interviews with their personal adviser. They will get support to prepare for suitable work. In return, they will receive a Work Related

Activity component in addition to their basic rate of benefit. If they refuse to go to the Work Focused Interviews, or to take part fully in the Work Focused Interviews, it may affect their entitlement to ESA.

2. ESA Support Group

If a person is placed in the Support Group because their illness or disability has a severe effect on their ability to work, they will not be expected to take part in any work related activity. They will receive a support component in addition to their basic rate of benefit and they won't have to go to interviews.

Job Seeker's Allowance

If a customer is found capable of work, they may be able to claim Job Seeker's Allowance. They will be given the option to make a claim when they are informed that their claim for ESA has been rejected.

Housing Benefit and Council Tax Benefit calculations may be affected. People moving to income-related benefits will receive maximum eligible help with rent and council tax. Customers moving off benefits will be contacted by the Local Authority to review their entitlement to Housing Benefit and Council Tax Benefit.

. - 10

Definitions

Atos

Atos Healthcare provides independent medical advice to the Department for Work and Pensions. They conduct disability assessments for people claiming a range of disability benefits including Employment & Support Allowance, Incapacity Benefit, Disability Living Allowance and Industrial Injuries Disablement Benefit.

Attendance Allowance

Attendance Allowance is a disability benefit for people who are 65 or over who are ill or disabled and need help with personal care or need supervision by another person to prevent them coming to harm. Attendance Allowance is a tax-free benefit paid by the Department for Work and Pensions. It is not means tested.

Department for Work and Pensions

The Department for Work and Pensions (DWP) is the government department responsible for welfare. It works with people of working age, employers, disabled people, pensioners, families and children, providing services through a number of executive agencies and non-departmental public bodies (Jobcentre Plus, the Pension Service and the Disability and Carers Service).

Disability Living Allowance

Disability Living Allowance (DLA) is a benefit for people aged under 65 who need care or supervision, or who have mobility problems. It has two components (care and mobility).

Employment and Support Allowance

Employment and support allowance (ESA) was introduced in October 2008. It is paid to people whose ability to work is limited by disability or ill health. It replaced both incapacity benefit and income support paid on the grounds of incapacity.

All claimants must have a limited capability for work. Whether or not you have a limited capability will be determined by an assessment process.

Fluctuating Condition

According to the DWP, a fluctuating condition means a situation where a person's clinical and/or behavioural state is expected to rapidly change, and is in need of continuous reassessment and evaluation.

Incapacity Benefit

Incapacity Benefit (IB) is a financial help given by the Government to someone who is unable to work because of a disability or long-term illness. If you couldn't work because of illness or disability before 31 January 2011, you may be receiving Incapacity Benefit. Since 31 January 2011 no new Incapacity Benefit claims have been accepted. IB has been replaced by ESA.

Income Support

Income Support (IS) is extra money to help people on a low income. It is for people who don't have to sign on as unemployed. Whether you qualify or not and how much you get depends on your circumstances.

Job Seeker Allowance

Jobseekers Allowance (JSA) is a benefit for people who are of working age but are out of work, or work less than 16 hours a week on average. If you're eligible, it is paid while you are looking for work.

Recovery

The Scottish Recovery Network describes recovery as follows: *r*ecovery is being able to live a meaningful and satisfying life, as defined by each person, in the presence or absence of symptoms. It is about having control over and input into your own life. Each individual's recovery, like his or her experience of the mental health problems or illness, is a unique and deeply personal process.

Work Capability Assessment

Work Capability Assessment (WCA) is the main assessment for ESA claims. It may include a medical assessment if more information is needed about a person's illness or disability before a decision can be made on their capability for work.

An ATOS approved healthcare professional, who has been trained in handling Employment and Support Allowance claims, will assess how an illness or disability affects a person's capability for work or work related activity, and provide advice to the DWP. If the healthcare professional feels that the DWP will need more information to make a decision on your benefit claim, they will recommend that you attend a face-to-face medical assessment.

The assessment process is as follows:

Nearly everyone who applies for ESA will be asked to complete a form about their ability to complete everyday tasks and then to attend an assessment carried out by a doctor or nurse.

At this assessment the doctor or nurse will ask a series of questions about the person's medical history and how their illness or disability affects their everyday life. They may also conduct a short medical examination. They will then produce a report the first part of which outlines what the person told them. In the second part of the report they then outline how well they believe the person can perform a number of everyday tasks. They need to provide evidence for their decisions based on what the person has said, what they have observed during the assessment and what they know about the person's condition.

The report is then sent to a Jobcentre Plus decision maker who will decide whether to grant ESA.

The decision by the Jobcentre Plus decision maker will be mainly based on what this report says. What a person says is not meant to be the only factor in deciding whether they are fit for work but if it fits with what is known about their medical condition then it is meant to play an important part. It is therefore very important that the report gives an accurate reflection of what the person tells the nurse or doctor during the assessment.

What did people tell us?

People told us that they felt there are a number of problems with the application of the Employment Support Allowance criteria to people who have mental health conditions.

These included:

- > A lack of flexibility, especially around fluctuating conditions
- > A lack of knowledge about mental health
- > A stressful and unsupportive assessment process
- > The massively negative impact the process had on them and their health

Flexibility for Mental Health?

- People told us that in general they do not feel the system and questions which are used for ESA are flexible enough for people with mental health issues.
- ➤ People who had undergone WCA told us that the examiners are not interested in specific symptoms or problems, just in getting answers to the questions they have been directed to ask.
- The questions were reported to be only set up for physical conditions; totally inflexible; complex and contradicting themselves and not taking mental health needs into account.

'It stresses out already vulnerable people'

- Many people had been assessed by a professional who did not have specific training in mental health, including burns nurses and physiotherapists.
- ➤ People felt strongly that mental health professionals should be carrying out assessments related to mental health rather than other medical professionals.
- People responding felt that the system could be flexible enough only if staff have sufficient knowledge and also only if the questions are reformed to be relevant.

100%

of people felt that the system is not flexible enough for people with mental health issues

Fluctuating Conditions?

- All respondents felt that having a fluctuating condition was a disadvantage which made it hard to get a fair assessment.
- Many people pointed out that by definition if you are able to go along to the assessment you will be having a good day, and therefore the assessment will not accurately reflect your circumstances.

'When the interviewee goes along the chances are they are having a good day, as if it was a bad one they wouldn't be there'

- People felt that the assessment process is not designed to take fluctuating conditions into account and it is difficult to convey the impact of a fluctuating condition in the assessment.
- ➤ People were also concerned by the 'snapshot' nature of the assessment which only captures how you are on one day, rather than over a period of time.
- Some people also pointed out if you are having a bad day you may not be able to get to the appointment and will then be penalised.

100%

of people felt that the system is not designed to take fluctuating conditions into account

The Assessment Process

The majority of respondents said that they had found the assessment process a difficult experience for a variety of reasons.

The Appointment System:

From the very beginning of the process people reported they had encountered problems.

'Too stressful even to think about'

- People reported that when they called the appointments line to explain reasons they might need to change an appointment, call handlers were not understanding.
- ➤ A number of people reported that they had tried to change their appointment time, due to either living a large distance from the assessment centre, or due to reasons relating to their condition or the need to be accompanied to the assessment, and had met with resistance and negative attitudes.
- One person described it as a 'frightening experience' and stated that they were only able to get a suitable appointment time after the involvement of their MP.

25%

of people had trouble just organising a suitable appointment time

The Actual Work Capability Assessment:

- In terms of the actual assessment people felt that the questions were not necessarily appropriate reporting them as 'odd' and 'don't seem relevant' and another person describing the questions as 'not related to my disability and not specific enough'.
- People also felt that there were too many questions and that the questions are not designed for mental health conditions.

'I fear the assessment will not understand or properly assess people like me'

- Others felt that it was very difficult to answer questions in the assessment situation and that they did not want to 'make it seem like I can't run my own life'.
- After the assessment people reported that they found that 'none of the answers on the report reflected what I said'.

90%

of people said that the assessment process was not an easy experience for them

Overall Assessment Experience:

- People also reported that the experience of going for an assessment is very daunting for them saying that 'assessments are never easy for me' and that 'I get nervous going to new places' and that they didn't know what to expect.
- ➤ A number of people described the assessment process as frightening and incredibly stressful and stated that it had a hugely detrimental effect on their health this included the actual assessment, the stress of waiting for and organising the assessment, as well as going through the appeals process.

'They ask questions, type all the time and make you feel like you have done something wrong'

- Many people who responded to the questionnaire had successfully appealed their initial assessment, including one person who had to turn to her MP to get an accurate result.
- Some people also reported that they had to postpone their assessment due to stress and worry about the assessment process, stating that they became ill with worry about their appointment and that staff they contacted to postpone the appointment were not sympathetic to this.
- Others reported that they felt it would only be even more stressful to postpone the assessment, but that they were only able to attend due to having support with them, and as one person put it 'I was too scared to postpone'.

Scores please... The Points System

- A lot of concerns were expressed about the points system which is used. People felt that this system is unfair and biased towards physical health and physical disabilities.
- ➤ People reported that they felt the points system does not work and needs to be more flexible, and also that it is unfair not to get an explanation of the codes that are used.

'It's unfair – an exercise with no variation. They make their decision before you've sat down'

- The points system also meant that some people found that none of the answers they gave were reflected on the final report due to the way the points system works.
- People felt that it would be better to have actual definitions relating to health issues rather than yes or no questions.

100%

of people felt that the points system is not geared up for mental health conditions

Appeals

Many respondents had successfully appealed the result of their initial assessment and received a higher score on appeal than they had been awarded at assessment.

'Information relevant to my diagnosis had been dismissed'

- ➤ A number of people found out at the appeal stage that relevant information had been dismissed or excluded from the initial assessment and report, and that report findings brought to the appeal were in fact contradictory.
- This only adds to concerns by respondents that the assessment process is not suitable for fluctuating conditions including mental health conditions and that assessments are not being carried out by mental health specialists.

Over 50%

of people had successfully appealed and been given a higher score on appeal

Employment Support?

People who responded to the survey also commented on whether they felt supported to get back into employment.

- ➤ The majority of respondents said no, with a very small number saying yes.
- People felt that they were being forced back into employment before they were ready and there was a lack of understanding that getting back into employment might need to be a very slow process for some people.

'I am terrified of this due to the pressure'

- People expressed concern that they were not receiving the right kind of support to get back into employment and that they felt the support is very conditional, that there is no allowance for possible relapses.
- People's experiences in the WCA only served to strengthen these fears.

Over 70%

of people did not feel they were being supported to get back into employment

Professional Knowledge

- The majority of respondents felt that the professionals who assessed them did not have the knowledge necessary to make an accurate assessment.
- People reported that that staff only seemed to have general knowledge and that they 'just went through the questions' and did not ask about specific and relevant conditions.

'It's easier to agree with the assessor than argue'

- Some people had been assessed on their mental health by professionals such as burns specialist nurses or gynaecologists.
- People also felt that it is not possible for an assessor to have the right knowledge about you and assess your condition accurately when they have never met you.

Over 75%

of people felt that the professional assessing them did not have the right knowledge

Supporting Evidence

- ➤ Responses about taking a support person or supporting evidence to the assessment showed that very mixed information is available.
- Some people said they were able to take supporting evidence and someone to support them, while others reported that they were not aware they could take someone for support or supporting documents about their condition.

'I didn't know I could take someone or any documents'

➤ Those that did take supporting evidence reported that evidence had been ignored and also that they had been told it was not acceptable to do this.

Over 70%

of people found that their supporting evidence was not taken into account

Impact of the Process

The most striking thing about the survey was the cycle that people reported they were felt they were trapped in of anticipation of the assessment, the judgement of the assessment and the stress of the whole process.

- 'How can they say I'm fit for work when my state is unpredictable from one day to another?'
- 'I'm scared of the appeal as there won't be a focus on my mental health and brain injury'
- > 'You have to promote your ill-health'
- 'It feels like a judgement'
- 'It's designed to fail people'
- 'It's quick to dismiss genuine people'
- 'With my disabilities being hidden it takes much more time explaining and this is not always allowed because people are pressured by time'
- 'I would prefer to be in paid employment, but employers discriminate'
- 'The process has made my problems worse'
- 'I need time to work through my issues'
- 'Anticipation of the process is making people ill'
- 'I have never been assessed by a doctor'
- 'I've been ill for fourteen years how can I suddenly be expected to be fit for work?'
- > 'I feel I am being punished for having a long term condition'
- 'I don't think anyone wants to be out of work it's a horrible state'

Individual Advocacy

The CAPS Individual Independent Advocacy Service working in East Lothian and Midlothian reported a huge increase of over 75% in the number of cases they were dealing with relating to ESA from October 2010 – March 2011. Advocacy workers have helped people to apply for ESA, access welfare and benefits advice and supported people through appeals. All these appeals have been successful.

Individual advocacy workers reported the same concerns about ESA and the WCA as people who had been assessed.

Individual advocacy gets involved at different stages ranging from the very beginning to the appeal stage. They get people to an advisor/welfare rights service and go to appeals and assessments with them.

The individual advocates reported that the whole process is very scary and stressful for people and outlined their concerns about the process.

Assessment Process:

'The assessor did ask about mental health but I think they'd gone off script'

- There is a lack of detailed questions and follow up questions such as: 'Do you get out and about most days?' 'Yes'. However there are no follow up questions to establish HOW people get out and about, how difficult it is for them and if they need support to do so.
- ➤ Often people are asked at the beginning of an assessment 'Did you get here OK?' This is seen as courtesy by the person being assessed, but it is used to show people go out and often people just say 'yes' not how hard it was to get there in the first place.
- Sometimes people can't go due to illness then they need support to appeal to prevent them being penalised.
- ➤ The assessments can be at 9am in Edinburgh which can be difficult all assessments and appeals are in Edinburgh for people from Midlothian and East Lothian.
- The assessment is an exercise in how to ask as few questions as possible in order to tick the boxes and the training is mainly about filling in the form rather than eliciting a clear picture of people's circumstances.
- ➤ People often have to wait a long time to see someone up to 30 minutes whilst nervous and anxious. You can leave and come back if they are running more than 15 minutes late but people don't want to do that they just want it to be over.
- ➤ There is also nowhere quiet to discuss things beforehand it's stressful sitting in a waiting room with others.
- People have told us that they don't want to have to claim benefits or be unable to work, it is a very humiliating process for them.
- With the 'Fitness for Work' system which is different from a GP signoff, GP opinion is being over-ridden. It can be really hard for people to

- understand this and it can make people feel they are not being believed which adds to their stress.
- ➤ People's response under pressure is to stand up for themselves which works against them.
- > People feel the questions are weighted towards physical issues.

Appeals:

- Appeals can take six months, and although normally there is a benefit safety net in place, there have been some examples where this isn't guaranteed. Some people have ended up with no money and have had to take out repeated crisis loans. We are not sure if this is due to the drop in income or a lack of information about where to get other help.
- There is also the massive impact of psychological pressure on people.
- ➤ How come there is so much different between the assessment and the tribunal all of our appeals have been successful there is a big difference in points.
- During the assessment medical evidence is ignored, but it can be used at tribunal, this doesn't make very much sense.
- ➤ The appeal process can take over six months and the appeal then looks retrospectively at the time of assessment and things can really change in that time.

Falling Through the Cracks:

- ➤ The individual advocates also highlighted their concerns that due to a lack of information and support people are spending time with no income and support and how advocacy can support people in this situation.
- Advocacy and welfare rights have very different roles.

- ➤ Applying to appeal the outcome of an ESA assessment won't mean being signposted to welfare rights and people are out of the loop with no income. Advocacy involvement means they can be signposted in this situation.
- ➤ This information about welfare rights and other support isn't being given to people about the assessment and appeal they are not being told about the available support.
- Without support people wouldn't be able to go to assessment or engage with the process and would fall through the cracks.
- ➤ People get into debt when benefits are stopped and changes in income can cause complications with Housing Benefit and Council Tax Benefit as people don't know where they stand.
- ➤ ESA assessment if not a full benefits check it is just in relation to employment and this needs to be made clear to people.
- ➢ It can be very difficult to get clear and consistent answers. When contacting Job Centre Plus and the Department of Work and Pensions answers are not always the same and the interpretation of the criteria isn't consistent. Disability Employment Advisors and welfare rights workers have also commented on this.
- ➤ Some people have literacy and concentration issues due to the sheer volume of information and this makes the process even harder for them.

Impact on Advocacy and Resources:

- ➤ There is a lot of pressure on resources to support people through this and there is likely to be an increase in demand.
- ➤ It is time consuming for advocacy to go to all these appointments but they have the continuity, relationships and trust that come with being independent.
- ➤ There has been a significant rise in ESA cases as a proportion of their work e.g. all staff all day in some cases.

Conclusions and Next Steps

From our research and consultation we have found that:

- ➤ The Work Capability Assessment for Employment and Support Allowance is not designed to accurately assess the needs of people with mental health conditions.
- ➤ The Work Capability Assessment process causes a high level of stress and anxiety in people with mental health conditions and in some cases makes their condition worse.
- ➤ The Work Capability Assessment does not cater for fluctuating conditions or accurately record how these conditions affect people's ability to work.
- The issues which have been raised in the Harrington Review and are being campaigned on by disabled people's organisations across the UK are also reflected in the views of people with mental health conditions.

As a result of these findings we will:

- Send our report to local and national politicians, and local health and social care services and ask for their responses.
- Share our findings with other campaigning and concerned groups.
- Continue to campaign and research these issues and lobby politicians.

Acknowledgments

We would like to thank all of the people who took the time to give us their views and tell us about their experiences.

Appendices

The Customer's Journey

This is how Jobcentre Plus explains the different steps people will have to go through:

- > Step 1 Customer hears of possible changes to their benefits.
- Step 2 Customer will receive a letter informing them that changes are about to happen and advising them on next steps.
- ➤ Step 3 Customer will get more information by phone.
- > Step 4 Customer will get a medical questionnaire to fill out.
- Step 5 Customer will receive a call from Atos Healthcare to arrange a Work Capability Assessment.
- > Step 6 Customer will attend the Work Capability Assessment.
- Step 7 If needed, customer will receive a call to gather any missing information and to explain the next steps.

Following the assessment, the journey can take two different directions. If a customer is entitled to ESA:

- Step 8 Customer will receive a call to advise on ESA and next steps.
- Step 9 Customer will be told they are to get ESA by letter and what group they are in.
- Step 10 Customer will be contacted to arrange a Work Focused Interview if they are placed in the Work Related Activity Group.
- ➤ Step 11 Customer attends the Work Focused Interview.

If a customer is not entitled to receive Employment and Support Allowance:

- Step 12 A Jobcentre Plus decision maker reviews the outcome of the customer's Work Capability Assessment and decides if they are entitles to ESA. They will advise the customer of their options. If they wish to claim Jobseeker's Allowance they will be transferred to someone who will take their claim details.
- ➤ <u>Step 13</u> Customer will receive a letter informing them of benefit changes and the Work Capability Assessment outcome.
- Step 14 Customer will receive a letter with their Jobseeker's Allowance award notification

If the customer wants to appeal the decision:

- Step 15 Customer will write or call with a request to appeal. They will continue to receive the assessment rate for ESA until a decision is made.
- Step 16 Upon receipt of an appeal, a Jobcentre Plus decision maker will look at the original decision and send a letter with their decision.

Reassessment of Incapacity Benefits

Since October 2010 and until spring 2014, people who receive Incapacity Benefit, Severe Disablement Allowance and Income Support paid on the grounds of illness or disability get assessed for Employment and Support Allowance.

The following benefits are being phased out:

- > Incapacity Benefit
- Income Support paid because of an illness or disability
- Severe Disablement Allowance

People who receive these benefits are getting their claims reviewed to see if they are eligible for Employment and Support Allowance.

- People who are capable of work move onto Jobseeker's Allowance where they satisfy the conditions of entitlement for that benefit.
- ➤ People who need more support while they prepare for work get that help on Employment and Support Allowance (ESA).
- Those people who are most disabled or terminally ill are not expected to look for work and will get the extra support they need on ESA

The change do not affect:

- People who are already being paid Employment and Support Allowance
- > People who reach state pension age before 6 April 2014.

- 34

Timetable of changes

Incapacity Benefit migration trials started in Aberdeen and Burnley from October 2010 using a sample of 1,700 claimants.

The main-roll out of migration of claimants from Incapacity benefit and income-related Income Support onto ESA began on 28 February 2011 and is due to finish in March 2014. People reaching state pension age between these two dates will be excluded from the migration. This is the only group exempt from migration so far.

In February 2011, letters were sent to 1,000 customers a week UK-wide, marking the commencement of their reassessment.

In April 2011, the number of cases increased to around 7,000 a week and from May, to around 11,000 cases a week.

Pilot Schemes in Aberdeen and Burnley

On 1 June 2011 The Department of Work and Pensions published a report on the pilot scheme run in Aberdeen and Burnley. The report is called "Trial incapacity benefits reassessment: customer and staff views and experiences" and was written by IFF Research Ltd. The full report is available at http://research.dwp.gov.uk/asd/asd5/rrs-index.asp (report RR741).

The pilot reassessment schemes in Aberdeen and Burnley started in October 2010. Ninety customers were interviewed, as well as Jobcentre Plus and Atos Healthcare staff working on trial reassessment.

Overall Jobcentre Plus staff thought that the decision-making process was working well, but had 'serious reservations' about whether the process could be scaled up to a national roll-out. In the trial areas both Jobcentre Plus and Atos Healthcare staff said they were 'going the extra mile' in many cases to review cases thoroughly, but staff felt the time spent chasing further evidence and clarifying the WCA report may have to be scaled back for national roll-out. The main findings were:

The overall customer journey for trial reassessment

Overall, the customer journey for trial reassessment worked well and customers were successfully guided through the different stages of the process by the letters and phone calls they received from Jobcentre Plus.

Initial stages of reassessment

Most customers received a letter notifying them they would be reassessed, followed by a phone call from Jobcentre Plus about a week later. Customers found these relatively easy to understand, and most thought the phone call added a welcome 'human element' to the process, with staff viewed as friendly and helpful.

Completing the ESA50 form and the Work Capability Assessment

Customers generally understood the importance of completing the ESA50 form accurately and within the four-week deadline. Although they did not always find the form easy to complete, they were mostly able to complete it. Some asked family or friends for help.

Experiences of attending a Work Capability Assessment were mixed. Although some customers commented positively on the empathy and professionalism of the Healthcare Professional (HCP) conducting their assessment, negative reports of the tone or manner of HCPs were reasonably common.

Decision making on reassessment cases

Decisions on ESA entitlement were made by Jobcentre Plus decision makers, taking into account the customer's ESA50 form and report of their WCA prepared by Atos Healthcare, as well as any other evidence provided by the customer or requested from their GP.

The two sites making trial reassessment decisions sometimes took different approaches to this process. One site tended to send cases back to Atos Healthcare for checking when they doubted a assessment recommendation, while the other tended to overturn the assessment recommendation on the basis of evidence such a GP report of the ESA50 form.

Customer views on the outcome

Customers placed in the ESA Support Group were generally content with their outcome and had no further questions, although they welcomed the 'human' element of the phone call.

Customers placed in the ESA Work Related Activity Group tended to be unsure about the implications of this, and some thought that the reference to 'Work' in their outcome letter meant they would be required to seek work immediately.

Customers disallowed ESA were generally stunned and/or angry, although a few were unsurprised and admitted they felt ready to work. This group were generally unable to formulate any questions on next steps during their outcome phone call, and may benefit from further contact from Jobcentre Plus once they have had time to consider their outcome.

Non co-operation with the reassessment process

Deliberate non co-operation with reassessment seemed low. Administrative issues, and the inability of some customers with particular conditions or chaotic lifestyles to cope with the process, were the main reasons for late or non-return of the ESA50, or non-attendance at the assessment.

Appeals

Some customers disallowed ESA appealed because they felt their outcome was unfair but commonly simply because they considered it the next logical step; communication from Jobcentre Plus staff throughout the reassessment process led customers to believe that they should appeal a disallowance decision, because they had 'nothing to lose'. Jobcentre Plus staff, and health professionals conducting assessments, appeared to use the message that customers could appeal as a means of deflecting or diffusing negative reactions to reassessment. However, most customers said they did not really have additional medical evidence to submit, beyond a Fit Note from their GP.

Harrington Review of the Work Capability Assessment

Harrington Review Year 1

The Harrington review, conducted by the academic Malcolm Harrington, an occupational health specialist, looked at whether the WCA was a fair system. The review was carried out because it had become clear that many people with serious illnesses were being judged fit for work when they were not before the introduction of the tests in 2008.

The review was carried out in November 2010. The full report and the government's response can be found at www.dwp.gov.uk/policy/welfare-reform/employment-and-support/wca-independent-review.

Harrington found that the assessments run by ATOS failed people with mental illnesses and long-term disabilities. One form which claimants needed to complete ran to 28 pages and almost half "found the questionnaire difficult or impossible to complete".

The review also found that some of the questions asked were not work related and just part of a generic computer system. For example people would be asked if they had "loaded a dishwasher or washing machine" that day.

The review found that 40% of those found fit for work by the system appealed and won – and added that 40% of people who went in front of a judge did so with "additional medical information".

Harrington said that the whole system needed to be reviewed so that Jobcentre Plus could consider all the health records needed before making a decision about whether someone should go back to work.

Harrington added that the current system could lead to psychological distress with affects on physical and mental health.

The report also recommends the appointment of lay "champions" to guide claimants through the process, and detailed explanations of why a benefit has been refused.

Government's Response to the Harrington Review (Year one)

In November 2010, the Government said it fully supported the recommendations of the Harrington Review, and would take them forward as quickly as possible to improve the ATOS assessment. Below is a list of the main recommendations. Further information can be found at www.dwp.gov.uk/docs/wca-review-timeline.pdf

Capable and confident decision makers

- Improving the decision making process.
- ➤ Do more to put the Decision Maker back at the heart of the system by reviewing their training to ensure it is appropriate and launch a forum to spread best practice called "Every decision counts".
- Find ways to improve communication between Decision Makers, ATOS and judges.

A more compassionate process

- Ensure the administration of the process is compassionate in its treatment of individuals. Increase the empathy in the system.
- Ensure there is greater communication with individuals undergoing reassessment from incapacity benefits so they understand the process and their responsibilities. Every individual going through reassessment will get a call at the beginning of the process, at the end of the process and a further call if they appeal.

Improve the ATOS assessment

- ➤ Ensure ATOS has in place "champions" with additional expertise in mental, cognitive and intellectual conditions to improve the service to individuals and to provide opportunities for staff to further develop their skills by spring 2011.
- Ensure that ATOS pilot the audio recording of assessments to understand the benefits and practical challenges this could bring.
- ➤ Ensure that ATOS create and publicise a Customer Charter, so that people are clear what can be expected from their ATOS assessment and what their responsibilities are.

Examining the descriptors

Professor Harrington launched a group to look in detail at the mental, intellectual and cognitive descriptors. This group will make recommendations to Professor Harrington about any refinements to the descriptors. He will then assess these and make recommendations to Ministers.

Interim Report on Year 1 Recommendations

In May 2011, the Minister for Employment, Chris Grayling, asked Professor Harrington to provide an interim report on the implementation of his Year 1 recommendations. The report was published on 7 June 2011. A full version is available at www.dwp.gov.uk/docs/wca-review-interim-report-may-2011.pdf.

This concludes that real progress has been made in implementing all of the recommendations. Some of main findings are:

Professor Harrington thinks that the Department for Work and Pensions and Job Centre Plus have gone a long way towards implementing all the recommendations related to their areas of activity. New learning and development packages have been produced to retrain the Decision Makers and additional training is to be provided for the line managers. New scripts and letters have been designed to improve communication with the claimants.

One area of potential concern in the Job Centre Plus is the 'silo' mentality in some quarters where some staff do not have an understanding of the whole WCA process, but only their section. Work will start soon to improve this.

Atos Healthcare have nearly completed work on all the recommendations related to them. The Mental Function Champions are either in place or will be soon – but at a *regional* level and not in every Assessment Centre.

The Atos Customer Charter is now in place and being displayed at all Assessment Centres. A pilot of the audio recording of face-to-face assessments has also been completed in Newcastle.

Tribunal judges are working towards improving communications between the judges and the decisions makers. Training programmes for both the medical members and the judges will be discussed.

Research protocols to look at the fate of people who apply for ESA but drop out of the WCA process before their face-to-face assessment and those who are deemed borderline between the three categories (Fit for Work, Work Related Activity, and Support group) have been drafted and agreed.

Finally, a review of the computer assessment system (LiMA) is underway to see if it drives the assessors' behaviour or if the assessor can drive the computer programme?

Harrington Review Year 2: Call for Evidence

The initial Harrington review was the first of five annual reviews. Improving the Work Capability Assessment will be an ongoing process to ensure that the system works as well as possible for people going through it.

As part of his second independent review of the Work Capability Assessment, Professor Harrington has launched a call for evidence running from 14 July 2011 until 16 September 2011. He is going to look mainly into:

- > the implementation of his Year 1 recommendations and the impact they are having
- > what, if any, further work is required in future reviews
- > the face-to-face assessment.

The call for evidence asks individuals and organisations that have been involved in the first review questions around the following topics:

- ➤ Have people seen any changes in the way the Work Capability
 Assessment works because of what was said in the first review?
- ➤ Are there any other areas of work that people think the review should look at next year?
- Last year the review looked at how important the face-to-face assessment was. Do people think it have got that right now? Do they know of any worries about the face-to-face assessment.
- ➤ Have people heard about any worries to do with the computer support for the Work Capability Assessment?
- > Should it change the way the face-to-face assessment is explained?
- ➤ What one thing would you change about the Work Capability Assessment to make it fairer and better?

- 41

Citizens Advice's Survey of Medical Reports

Citizens Advice Bureaux (CAB) regularly report gross inaccuracies in many of the medical reports they see in ESA appeal papers which can impact on people's chances of receiving ESA.

They are keen to monitor the process, to see whether people are treated fairly and whether any medical evidence they have is taken properly into account. They also want to build a picture of the administration of the process and find out how people are personally affected. This will allow them to campaign for improvements to the way ESA is managed. Earlier in 2011, they ran a survey asking people who are in the process of applying for ESA, or are about to apply, about the accuracy of medical report.

They want to find out:

- if there are any factual errors,
- if anything people said has been missed out
- if there were any areas people felt they weren't given time to talk about
- if any untrue conclusions have been drawn because assumptions have been made

They are concerned that too many reports contain factual errors and omissions which then lead to unfair decisions. They want to try and get a clearer idea of the level of accuracy nationally and also if particular doctors in your area are more prone to inaccuracy. A report on the survey is pending.

CAB is also asking people through the ESA claiming process to fill in a diary. It is a simple survey, with a section that can be completed at each stage of the claiming process or at the end of the process. Responses are completely confidential and anonymous and will be used to campaign for improvements. People can complete the diary online, or, can download and print off a paper version which you can return at a freepost address. It is available at

www.citizensadvice.org.uk/index/campaigns/current_campaigns/fairwelfare/cam-fw-esaactions/cam-fw-esadiary.htm

Initial Focus Group

Wednesday 3 November 2010

Notes from Meeting:

- Process make problems I have worse
 - "exacerbates all my symptoms"
- Appalling experience Atos
 - Process is meant to take 45 minutes and has been known to take only 10 minutes
 - > Assessment misrepresented what I said
 - ➤ Got 0 points at assessment. When I went to appeal and got reassessed I got 39 points now have to be reassessed again only a year later
 - "I don't need the lump sum of back payment, I need time to work through my issues"
- Constantly under pressure and stress
 - Stress is a trigger for mental health issues this is the opposite of the recovery process which encourages you to identify/avoid triggers
- ATOS is struggling with process as it is. It will get worse as things accelerate
 - The numbers from the pilots will not necessarily be accurate or helpful for other areas
- Someone who's known you for years would probably have a much more accurate assessment report
- Someone took 2 letters of support from CPN and Psychiatrist who have known her for years and they were ignored
 - "It's not part of the process"
 - ➤ The question and answers are set up in such a way that they can define your answers and miss the point
- Need to use doctors who are specialised in your condition. They do it to detain people so why to assess them for ESA?

- can understand using independent doctors, but couldn't they use specialists if they're insisting on black and white tick boxes – others won't know about mental health
- "If you're not going to let me use my doctor, at least let me use a specialist"
- "I have never seen a doctor through ATOS only a nurse and a physiotherapist"
- "staff allocation is appalling"
- "I've been ill 14 years. How can I be suddenly expected to be fit for work?" If you have a condition you cannot recover from, you should not be punished for it.
- Work related activity group it is supposed to be a progression towards getting back into employment – some people will not get better
 - "focus seems to be 'oh you're ill, that's a shame give it three weeks – I got ill 14 years ago and haven't progressed."
 - "I'm already doing the amount of work I can manage"
 - "will doing some voluntary work or work mean you have to go into the Work Related Activity Group – even if you can't do more?"
- We have to through muppetry interviews
 "That's another day when I have to get up and stress out and end up physically, mentally and emotionally knackered"
- Need to write to DWP to ask them ATOS staff is getting incentives if they get people on the Work Related Activity Group.
 "Is ATOS incentivised to get people off benefits?"
- We are seen as benefits fraudsters and scapegoats for government to save money – this is perpetuated by the media

"you lose your worth through illness"

"how much do all these appeals cost?"

"get the feeling we are being singled out"

- There are days I can't get out of bed so by default I will be assessed on a good day when I manage to get out of my house
 - ➤ "Some days I won't be able to attend that medical, cos I won't be able to get out of the house by definition my assessment will be on a good day and therefore inaccurate"
- Potential of fluctuating conditions
 - ➤ Not making it to assessment seen as did not attend?

- Need to work more closely with health professionals who know person
- Not being in a "bad day" when assessed
- Take opinions/supportive letters from health professionals into consideration
- Need for more support/advice but cuts in services (e.g., CAB, Welfare Rights)
- Link between process and triggers such as stress/problems using public transport/problems being in a busy room
- ➤ Need a phased approach, time to get on your feet
- Need for an option for part-time work and not just black and white approach (fit/not fit for work)
- Being able to do a small amount of work doesn't mean being able to work full time
- What support is available to get back to work? What about therapeutic time?
- Need to see an individual basis what support and type of work is possible
- Are they going to find a job for you? What about stigma?
- "You need time to recover and get back on your feet and back to where you want to be"
- "I don't think anyone wants to be out of work it's a horrible state"
- "Stress and pressure in the workplace which you don't get in voluntary jobs aren't taken into account."
- "should be done on an individual basis rather than generalise"
- "half of the year you are on benefits and the other half going what the hell is going on?"
- "are they going to find a job for you? What about stigma?"
- "it's just a piece of software that decides if you're getting the benefit not a human being"
- "I could only come along today (to meeting about ESA) because I was accompanied"
- "you've got to do all this when you're already ill"
- "I've not been through this and it worries me sick I dread this coming through the door"
- "basically every time this happens it knocks my ability to even start thinking about the things I want to do to get back to work right out the window"

ATOS

- Have they done a rapid impact assessment on mental health area?
- Staff training/ mental health knowledge?

- How will they work with organisations that already support people looking to get back to work?
- Is the medical assessment actually legal?
- Would be better than a points system should DWP read these docs
- Point system not accommodating fluctuating problems
- Need to explain limitations people might face at work eg need somebody to support them
- Anticipation of assessment is making people worry sick/+stressed and unwell

46

Questionnaire Developed from Focus Group



WORK CAPABILITY ASSESSMENT AND EMPLOYMENT SUPPORT ALLOWANCE

WHAT DO YOU THINK ABOUT IT?

Over the past couple of years there have been some changes to the benefits system. One of the biggest changes has been the introduction of **Employment Support Allowance (ESA)**. Everyone who applies for ESA has to go through a **Work Capability Assessment** to decide whether they can do some type of work.

CAPS has met with a group of people who have had experience of the Work Capability Assessment and gathered their views on how they feel the system is working. Based on this initial focus group, we want to find out more about how the process is affecting people with mental health issues so we can keep informing the Government about how the system is working or if it needs to change.

We are trying to reach as many people as possible throughout Edinburgh, Midlothian and East Lothian. We would appreciate if you could fill in this questionnaire. You can also fill it in online on SurveyMonkey at www.surveymonkey.com/s/2VYBSR8.

You can return your answers using our freepost address. No stamp is required.

FREEPOST SCO1853

CAPS – The Consultation and Advocacy Promotion Service 5 Cadzow Place, Edinburgh EH7 0BR

You can also email us at laetitia@capsadvocacy.org. If you would prefer to talk to someone about your experience or if you would like to have a meeting arranged in your area, please contact Laëtitia, Naomi or Nikki at CAPS on 0131 538 7177.

Contact deta	ils (OPTI).	ONAL)		
Name:			 	
Telephone: .			 	

Email address:				
I live in Edinburgh ☐ East Lothian ☐ Midlothian ☐ I want to be kept updated on the campaign Yes ☐ No ☐ I would like to attend focus groups in my area Yes ☐ No ☐				
THE ASSESSMENT PROCESS				
Have you found the assessment process an easy experience? Why?				
Have you ever had to postpone an assessment because of the stress of having to go through it?				
Do you think the medical professionals doing the assessment have the correct knowledge of how your mental health affects you ability to work? Have you ever been assessed by someone you felt did not have the right knowledge?				
Were you ever allowed to have someone supporting you at the assessment? Were you ever allowed to produce letters of support from medical staff who know you?				

Any other comments or experiences on the assessment process: **EMPLOYMENT SUPPORT ALLOWANCE AND MENTAL HEALTH**

Do you think having a fluctuating condition, with good and bad

days, is playing against you when you get assessed for Employment Support Allowance?
Do you think the system is flexible enough for people with mental health issues?
Do you find the point system used to assess people fair?
Do you feel supported to get back into employment?
Have you ever had to appeal against an assessment? If so, was your score different when you were re-assessed?
Any other comments:

49

	or parts of my story as part of their stand that my name will not be
Signed:	Date:

CAPS independent advocacy

The Consultation & Advocacy Promotion Service