

Not fit for work

Mental health and the Work Capability Assessment

For Rethink Mental Illness

February 2017



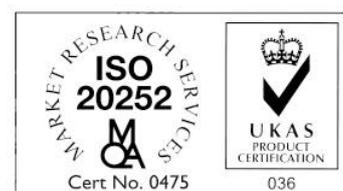
RESEARCH

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I. Executive summary

WCA: The Form

The research found that for many, the paper form doesn't allow for people with mental health conditions to discuss the impact of them on their daily life; therefore they aren't able to explain about the impact of their conditions on potentially working. Participants indicated they noted the forms have a greater emphasis on physical health conditions, and questions about mental health are phrased in a way which mainly captures the physical effects of mental health.

Support for WCA Claimants

All participants stated they would prefer to have a friend, relative, carer or advocate to help them through both the paper form and face-to-face assessment. Support with the paper form was thought to be important as it can be difficult to accurately put down on paper descriptions of their own condition and symptoms; not to mention emotionally draining. The importance of support at the first stage was highlighted by those who had completed the form both with and without support, finding the former to be much more difficult and did not yield the outcome they felt they should have been given. Having an advocate with them during the face-to-face assessment was also noted as being crucial, some feeling it should be strongly advised as it is a way of helping with a very stressful situation; but also means there is a second person witnessing the assessment should the claimant be dissatisfied with the meeting.

WCA: Medical Evidence

It was discovered that participants often found collating their own medical information a difficult and stressful task which had an overall negative effect on their mental health; a minority had paid for copies of documents from their GP at a time when money was tight for them. Participants found it difficult to understand why they were tasked with gathering the evidence which can be found in their medical records or relevant professionals' records.

WCA: The Face-to-Face Assessment

The face-to-face assessment was often a difficult and stressful occasion, seen by many as a form of 'medical', and although many felt that trained staff could assess the forms; face-to-face assessors should have mental health skills, qualifications and experience. Most participants were unhappy with the assessor being a generic clinician serving as an assessor, such as physiotherapist or nurse; as mental health is so varied that some form of specialist skills and knowledge are required for the experience to be as positive as possible and truly reflective of a person's current situation. Participants also noted not being treated as a person or individual, just as a 'claimant'; leaving them feeling low and dehumanised.

WCA: Appeals

Participants found appeals to be lengthy and stressful, although most who had been through them found they did get the outcome they wanted, and the decision to be placed in the ESA support group was made following the appeal. This meant that participants wondered why appeals are often able to come to these decisions but those assessing the paper form and face-to-face assessment are not. Appeals, although often successful for those engaged with for this research, were felt to be unnecessary as the information presented had not changed since the initial assessment; so questions were raised about the effectiveness of the assessment process overall.

Support at Work & Healthcare Services

Almost all participants were able to recount their experiences of being in work and becoming ill because of their mental health conditions, although some had positive experiences with certain

employers; the support overall was inconsistent and resulted in people feeling confused about disclosing conditions and how to discuss the impact of their condition on working with their managers. Participants cited the stigma which is still attached to mental health conditions, noting that although this has improved over the years; it is still a huge barrier between them as employees and current / potential employers. Participants wanted to know their condition would be understood, and any steps to make adjustments for them at work would be discreet and sensible. Participants noted the value of being able to confidently access healthcare services to help and support them with certain aspects and symptoms of their condition. Early intervention support and services were also noted as being important for people with mental health conditions, and particularly so when people want to take steps to get back into work.

The Categories & Support to Move into Work

Although participants were able to discuss what they would be happy to undertake as part of supporting them into work, only a minority could discuss actual steps taken by professionals to do so; emphasising the need for good healthcare support. Some mentioned charitable organisations as helpful in getting them back into the routine of working, but being placed in either the ESA Support group or the Work Related Activity Group had not given those who were in them any support to start thinking about or taking steps to get into employment. For many, their experiences of the Job Centre had been negative or their support as ineffective; leaving them feeling quite low in confidence about ever finding work. Those who had been incorrectly declared fit for work had in some cases been instructed to pay money back to the DWP, or found that the Job Centre and the work programmes were inherently not appropriate for people with mental health conditions.

2. Introduction

Qa Research (Qa) was commissioned by Rethink Mental Illness to undertake research into the experiences of people with mental health conditions of the Work Capability Assessment. (see below). Rethink Mental Illness commissioned the research as part of their approach to responding to the Government's Green Paper - Work, health and disability: improving lives and the ongoing consultation.

Part of Rethink Mental Illness' work involves campaigning on behalf of people affected by mental illness. As part of this remit, Rethink Mental Illness noticed there may be some actions mentioned in the Green Paper which could impact people affected by mental illness. Therefore, Rethink Mental Illness wished to consult via an independent agency, with those who may be affected; to understand their past and current experiences of the Work Capability Assessment. As a secondary aspect to the research, Rethink Mental Illness also wished to explore the link between work and health, and also look in some detail at the support provided to people with mental health conditions whilst in employment; and also suggestions from participants as to what constitutes effective support whilst working.

The Work Capability Assessment (WCA)

The Work Capability Assessment is the mechanism used by the Department for Work and Pensions to determine whether a person is eligible to receive the benefit Employment Support Allowance (ESA) – which is paid to people who are not well enough to work. Those who apply for ESA start off being paid the same amount as those claiming Job Seekers Allowance (JSA); the WCA also determines the rate which ESA claimants are paid. The Work Capability Assessment process comprises the following three stages:

1. **Paper assessment** – claimants are required to complete a paper form (ESA50), included within which are a list of 'descriptors'; used to determine to the extent to which a claimant's ability to work is affected by restrictions in their physical and mental abilities. Claimants are also asked to collate medical evidence to support their claim.
2. **Face to face assessment** – following the paper assessment, the majority of claimants are subsequently invited to a face to face assessment carried out by a medical practitioner working for the contracted company responsible for the WCAs (Maximus, previously Atos). The information gathered from the face to face interview, plus the paper forms and medical evidence; are used by the assessor to make recommendations to the DWP about what support the claimant should receive and what steps should be taken towards working.
3. **Consideration of recommendations** – the assessor's recommendations are then reviewed and considered by the DWP who inform the claimant as to which category they have been placed in.

The decision made will determine which of the following categories the applicants are placed in:

1. **Fit to work** – ESA applicants are moved onto JSA permanently and receive this rate of benefit payment. As part of this referral, most claimants are required to take part in the Work Programme after being unemployed after 12 months. This is delivered through the Job Centre Plus; or a contracted provider.
2. **ESA Support Group** – claimants in this group are those found too unwell to work or take any steps towards work, meaning they are paid the highest rate of ESA.
3. **Work Related Activity Group (WRAG)** – those people placed in this group are required to attend work-focused interviews and in some cases training; they are paid a lower rate than those in the ESA Support Group.

3. Aims and objectives

The main aim of the research was:

“...to gain an understanding of the experiences of the Work Capability Assessment for people with mental health conditions which severely affect their lives – which will inform part of Rethink Mental Illness’ contribution to the Government’s Work, health and disability: improving lives Green Paper..”

Within this main aim lay the following objectives:

- Explore the issues with the WCA, both positive and negative
- Understand how the WCA could be improved
- Investigate experiences of people in the three different groups
- Discuss participants’ attitudes towards work, their experiences in the workplace and accessibility of services to aid their employment
- Assess the nature of the support they have received from the Work Coach, their relationship with them and their understanding of mental illness

4. Methodology

The research used wholly qualitative methods focused on engaging individuals or their relatives/carers/supporters who:

- are severely affected by their mental health conditions
- have experience of the Work Capability Assessment / experience of employment

The method was originally proposed to be a small, round table discussion style event. However, findings during recruitment indicated an additional, alternative approach would be required as not everyone felt comfortable or was able to attend an event. As such, the following two methods were used to accommodate for the target sample's preferences:

- A discussion group in York
- Telephone depth interviews

The fieldwork was conducted by three Qa researchers between 27th January and 2nd February, the geographical locations covered by the research included:

- Cornwall
- Coventry
- Manchester
- Sheffield
- Stockport
- York
- Warwickshire

Recruitment

Recruitment was undertaken by Qa researchers, with help from Rethink Mental Illness who assisted in identifying participants for telephone depth interviews once the methodology had been amended to include interviews. Rethink Mental Illness contacted some individuals known to them to check that they would be happy for Qa to call them. In addition, Qa put together a database of c.50 mental health related groups and organisations which operate in York, together with individuals living locally who we believed may be interested in the research.

Over a period of two weeks, Qa contacted these groups/organisations/individuals by phone, email and sometimes face to face where this was appropriate. Qa and Rethink Mental Illness designed a flyer/information sheet which was shared amongst these contacts and people were encouraged to share with individuals they thought the research might be relevant to.

Qa designed a recruitment questionnaire for participants which were either filled in over the phone with a researcher, or done by self-completion depending on preference. The form not only ensured recruitment of appropriate participants, but also acted as a profile form giving Qa some background and demographic details for analysis and to aid the moderator in understanding participants' needs. The questions in the form gathered the following information:

- Whether they had undergone a Work Capability Assessment
- The group they were placed into following the WCA
- Their mental health condition(s) and whether they are severely affected by their mental health condition(s)
- Age range
- Gender
- Ethnic group

During the recruitment period, some individuals agreed to attend the event and others indicated they would prefer to take part through a telephone depth interview. Those who wished to attend the group were emailed a participant information sheet/invitation with all the details on, plus reassurances around the format of the day, who would be there and what to expect.

Those individuals Rethink Mental Illness had identified were contacted firstly by the project manager at the community group who gained consent to share their contact details with Qa to undertake the interview. Depth interviewees were contacted in the later days of fieldwork. In total, we engaged with 17 individuals for this research – either through the discussion group or telephone depth interviews.

Achieved sample – discussion group¹

Participant	WCA	Working group referral	Severely affected by condition	Condition	Age group	Gender	Ethnic group
1	Y	Fit for Work, appealed, now: ESA Support Group	Yes	Severe depression	45-54	M	Black European
2	Y	Fit for Work, appealed, now: ESA Support Group	Yes	Borderline personality disorder, depression, anxiety	25-34	F	White British
3	Y	ESA Support Group	Yes	Bipolar	45-54	M	White British
4	Y	Fit for Work, currently appealing	Yes	Depression	55-64	F	White British

Base: 4

¹ Please note – when attributing quotes, BPD is borderline personality disorder, while Bipolar Disorder is spelt out in full

Achieved sample – telephone depths

Participant	WCA	Working group referral	Severely affected by condition	Condition	Age group	Gender	Ethnic group
5	Yes	ESA support group	Yes	Schizophrenia	55-64	F	White British
6	Yes	WRAG thinks, though maybe Support Group	Yes	Clinical severe depression, anxiety	35-44	M	Did not respond
7	No	N/A	Yes - not as badly now as on medication and switched careers	Anxiety, depression	25-34	M	White British
8	Yes (Incapacity benefit)	N/A	Yes very much so	PTSD, bereavement, depression, schizo affective disorder	35-44	M	White British
9	Yes (when still working age)	ESA support group	Yes	Bi-polar	65+	F	White British
10	Yes (currently waiting for decision on 2nd WCA)	N/A	Yes	Depression	45-54	F	British Asian (Pakistani)
11	Yes (relative)	ESA support group	Yes	Dyslexia, somatoform disorder (health anxiety), social anxiety, paranoia	25-34	m	White British
12	Yes	Fit for work/ appealed / fit for work	Yes	(Undiagnosed at the time) mental health, sciatica, type 2 bipolar disorder, cyclothymia	25-34	M	White British
13	Yes	ESA support group	Yes	Bipolar	45-54	F	White British
14	Yes	ESA support group	Yes	Neurological, poor short term and working memory, confusion, severe anxiety	45-54	M	White British
15	Yes (relative)	ESA support group / DWP changed / WRAG / appealed / ESA support group	Yes	BPD, Anxiety	25-34	F	White British
16	Yes	ESA support group	Yes	Anxiety	45-54	M	White British
17	Yes	ESA support group	Yes	Depression	45-4	M	White British

Base: 17

Tool design and fieldwork

Qa and Rethink Mental Illness drafted a discussion guide plus accompanying participatory appraisal tools (copy in the appendix of this report). The guide was later adapted slightly for the telephone depths with individuals and relatives/carers/supporters. Each group and interview was written up in separate detailed summary documents, including verbatim quotes to illustrate points made. The researchers involved in the fieldwork attended a face to face debrief session to discuss the key themes and findings emanating from the research, this process is a part of Qa's analysis and also helps reduce any interviewer bias which may otherwise occur.

A note on reading this report: We have reported on the key findings from the discussion group and telephone depths together under the related headings. In each section, where appropriate, verbatim comments have been included to help illustrate points made by the authors.

Please note that the results of qualitative research cannot be projected onto the overall population, due to the sample selection, interviewing methods and sample size.

5. Key findings

5.1 Profile of participants

Mental health conditions and impact

Participants in the group and the telephone depths were asked to talk a little bit about themselves, their condition and who in their lives supports them – who is the most and least helpful.

The activity revealed details about a range of conditions from severe depression and anxiety, to bipolar disorder and schizophrenia. Understandably, everyone reported their conditions affected them in very personal ways and everyone had differing experiences of support from family, friends and professionals; but all explained they were either currently severely affected by their condition, or had been in the past. For those who indicated at the time of the research they were feeling well, they explained this was through having learned to manage certain aspects of their conditions; but they know it will always be something which they will have with them.

Although there were differences in how their conditions impacted on their lives, there were some similarities in terms of high and low mood, and depending on this their physical ability to complete daily tasks such as getting out of bed, travelling anywhere or washing and getting dressed, was very much affected. These difficulties, or cognitive impairments, which are experienced by people with mental health conditions; can impact on their ability to undertake daily tasks such as getting ready for work.

Although there were clear differences between participants who have experienced symptoms for longer and perhaps have had a diagnosis for longer, and those who have not (the former reported being better equipped to manage the symptoms of their conditions) cognitive impairment was still cited by all participants as affecting them – regardless of where they are in their recovery. Being able to better manage symptoms was said to be down to experience, knowing what impacts them positively and negatively in terms of their mental health; meaning it is easier for them to figure out or find out when they need support and in what form.

5.2 Work Capability Assessment – paper form

Participants were invited to give their opinions on the paper form (ESA50) which applicants for Employment and Support Allowance are required to complete as part of the benefit claiming process before it is subsequently reviewed to determine whether a face to face assessment is required. The general consensus across all participants was that this form is not an appropriate tool for gleaning enough accurate information about a person's mental health condition; particularly regarding the impact of mental health conditions on people's lives. This section of the report explores this overarching theme in more detail.

Describing condition and its impact on the form

The ESA50 form, which is a 20 page document that asks a variety of open and closed questions about a claimant's health and/or disabilities requires individuals to write about their conditions themselves – or a friend/relative/carer, can complete the form on their behalf. The form can be

downloaded from the internet and printed off, but it is also posted out by the DWP to those who have requested a copy.

None of the participants we spoke to recalled having any particular issues in receiving the form, such as not receiving the form or having to request the form multiple times. There was some confusion over when you have to reapply year on year. There was lack of certainty about how to fill in the form in a subsequent year – would you repeat the same information already provided previously, or would you only add new material and assume that the assessors would look at the previous forms too?

Their main concerns were around the actual questions, the way the questions are asked and the effect of answering the questions on their mental health. For example, almost all of the participants talked about how answering the questions, which requires them to relive some very difficult times, often left them feeling – at best quite down – and at worst, extremely anxious and in one case – wanting to harm themselves. On further probing the main issues with the form were found to be the following:

- **Ambiguous questions** – a minority also felt as though some were deliberately phrased in certain ways in an attempt to trip them up.
- **Questions weighted unfairly towards the reporting of physical health conditions** – almost all of the participants mentioned this as a problem with the form, not only do the questions about issues relating to mental health account for a very small portion of the overall form; when questions relating to ‘the mind’ are asked, they are still perceived as being focused on physical or neurological conditions affecting the mind rather than mental health.
- **Those with the mental health condition often aren’t the best people to factually describe their condition and its impact in the way the form requires** – all of the participants felt this was one aspect of the paper form that is fundamentally at odds with how mental health conditions generally tend to impact people. This was explained by participants as being in reference to their own awareness (or lack of) of their symptoms and state of mind at different times. For them, having support to fill in the forms is crucial but not always possible if a person doesn’t have that kind of support available to them. Almost all participants found it difficult to understand what kind of day they are supposed to be answering about – would it be a good day, bad day? One view was that it might be best describing their worst kind of day and saying how many times a week or month they tend to feel this way.
- **Filling in the form for the first time is much different to doing so subsequent times** – participants who had experience filling in the ESA50 form, and also other similar assessment forms explained how their approach to completing them now is completely different to their first attempt, mainly as many participants did not originally get the decision they wanted or expected and subsequently had to ask for help – these sources of support are mentioned further into the report.
- **The form was perceived by some to be a health assessment** – a minority felt that the questions asked in the form constitute a *de facto* assessment of a person’s health, but without the correct procedures being followed which would be required if such a health assessment was typically to be undertaken by a GP or other health professional.
- **Repetition of information that has not changed in many years, such as the causes of illness or diagnoses of acute conditions such as schizophrenia** – Although this was the explicit opinion of just a minority of participants who indicated delving into their past was particularly painful, others did allude to similar feelings about

the paper form as a whole; that being the distress caused by putting personal details of their conditions on paper overrides the necessity of reiterating these for each new assessment – particularly if the person has undergone a number of assessments for other benefits (DLA/PIP). The main point being made was that repeating details shouldn't be necessary if a person has a long term condition which is not going to change in terms of medical diagnosis.

Key comments:

"I'm not quite confident about it [describing condition] cos they haven't really spoken to me about it." (F, 55-64, Schizophrenia)

"No...categorically not...they're like one word answers and how can you possibly give someone a snapshot of your life in a little box – you can't so no...they need changing!" (F, 45-54, Bipolar)

"I guess because for me, bi-polar, and some serious physical health problems as well, they fluctuate on a daily basis, so it's very difficult to give an overall picture of how my life is affected – cos they kind of ask how you are affected on a day-to-day basis...they're not formulated to give a full picture..." (F, 45-54, Bipolar)

"Some of the things that you want to put down that you're not allowed to put down...it doesn't allow for such things as how the illness actually affects you, how you feel at the time, how you can be suddenly fine one minute and the next minute something can click and you can be in a really dark place." (M, 45-54, severe depression)

"I think because mental illness isn't always every day and it's like 'can you learn how to do an everyday task such as setting an alarm clock?' that's nothing to do with having depression!" (F, 25-34, BPD)

"It's like 'behaving appropriately' you can feel like you want to kill yourself but still behave appropriately in public." (F, 25-34, BPD)

Completing the form – without support

As touched on in the bulleted list above, there was a clear theme raised by those participants who were more experienced in terms of completing the form; that of the difficulties people with mental health conditions can face in filling in the form without someone to assist them.

Only a minority of participants explained they had completed their most recent form by themselves; in those cases, they had not got the decision they wanted or expected. These participants explicitly stated that from their perspective, they should have been supported to complete the form; feeling the outcome may have been different if a friend/relative had been able to assist. The reason for feeling this way was that now, a few years on from their first assessment; they have a better understanding in terms of how difficult it can be to write about the impact of their own mental health condition; therefore absolutely see the benefit of having support at the paper form stage. One of the older participants who took part in the research explained how initially they hadn't found the form to be too difficult to complete, until the decision that they were Fit for Work was given; which has lead them to submitting an appeal.

Those who hadn't received support filling in the form cited two reasons. Firstly, some people did not feel they had anyone they could ask for help and as such, completed the form themselves;

included within this were older people without access to any virtual support. Secondly, others did not think they needed any assistance completing the form, because as they saw it; they were satisfied that the answers they gave were detailed enough for the assessor to understand their situation regarding their mental health condition.

Completing the form – with support

Most participants had sought a friend, support worker or relative's help with this task of form filling. Some supporters had filled out the whole form, in cases where participants found it too stressful; others had completed the form alongside the participants.

Some mentioned getting virtual advice and support from the charities and forums on the internet (Citizens' Advice, Mind, Rethink Mental Illness, online forums), but acknowledged that for some people internet advice would not be suitable.

Overall, the advice from participants to other people with mental health conditions considering completing the paper form was to ask someone else for help completing it. Getting everything down about one's own condition within the restrictive question and answer sections was seen to be too difficult to do by oneself. It was also thought helpful to have someone with you to talk to once it's all over, as confronting the realities of mental health conditions can often leave people feeling low, following completing the form.

From the perspective of relatives or carers supporting with form completion, it was advisable to provide as much extra documentation as possible, to compensate for the fact that the forms did not appear to be designed with mental health conditions in mind.

Key comments:

"Often...we are not the best people to be able to give that picture because we are not well, but we need this money to survive on, so it's a kind of double-edged sword really. (F, 45-54, Bipolar)

"I don't think the forms are great. There's not much space to write...they need to have a bit of background. There should be special consideration for people suffering with mental health because without us they'd be on the streets- they can't deal with forms." (Carer of - F, 25-34, Bipolar Disorder & Anxiety Disorder)

"I find it interesting between my two times between me doing my ESA...the first time, not knowing anything about it, I had to fill in one of these forms and do an assessment and just saying what I thought was enough and I get zero points. To then having exactly the same information but more awareness of how the system works, and being able to know what they needed me to say...I wouldn't have known that if it wasn't for the internet basically!" (F, 25-34, BPD)

"I had someone to help me do this, I asked someone at [charity] and also [friend] as well, and at times you get to a point where you are too emotional. I mean you can't put down here about the abuses, the nightmares, the lack of sleep things like that." (M, 45-54, severe depression)

Medical evidence, support of GPs and payment

Some participants mentioned gathering medical evidence as a particular point of contention in the application process, not just for the pressure felt by individuals in getting all of the correct information together in time; but for some the task of visiting their GP surgery, explaining to the receptionists and subsequent payment for producing the correct evidence was detrimental to their mental health. The practical and emotional sides of collating this evidence amounts to a significant burden placed on claimants at the very first stage of the assessment process.

For other participants in their most recent application for ESA, they didn't find the process of gathering medical evidence too tiring or stressful because they either already had it to hand or felt they could access it with ease. Again, this tended to be those who are more experienced in completing the paper assessment, and have the evidence because they've had to collect it in the past and have learnt to copy and save all their documents; and for those who live in supported living so their workers have easy access to the information.

All participants questioned whether this task should even have to be undertaken by any benefit claimant, especially people who have mental health conditions. Participants perceive that precise and complete records are available to health and care professionals in the form of medical notes, and that these could be made available to DWP instead of requesting for individuals to gather their own evidence. Some participants were pleased to note on the form that their doctor would be contacted; they felt their doctor was the expert and would have a valuable input into the assessment.

Key comments:

"You're always asked to collate medical evidence, whether you can get it or not is another matter...fortunately, I've got into the practice of anytime I see anybody I photocopy it and leave it in the file...I keep everything now purposefully for that...in the first instance when I'd never claimed ESA before...I didn't actually have a clue – but now I'm a bit of an old hand, it doesn't make it any better but I am slightly more familiar with what's needed." (F, 45-54, Bipolar)

"Very often you know you're asked to, I think it's ten pounds you have to pay for copies of things. At a time when you've got no money it's a joke!" (F, 45-54, Bipolar)

"...I don't drive, and I have to get public transport to my doctors so it's all additional stress. You can't get in to see your doctor anyway so you've got to speak to the doctor's staff and say this is what I need, so it does have a negative impact because it's another additional worry, it's not just the form, it's everything else that goes with it that you've got to make sure you get in within the time limits." (F, 45-54, Bipolar)

"I think you should be able to give written consent and they should be able to contact your specialists themselves...it shouldn't be up to the person who is too unwell to work, to have to go and get all this stuff...it would take a big burden off me." (F, 45-54, Bipolar)

Response from DWP about any queries and how responses affect decisions

Some participants, particularly those who required the most help in filling in the forms, felt they could have been given a better explanation about what would happen following the decisions at paper form stage – so they had an idea of what to expect. Some were initially disappointed to hear they had to go to a face to face assessment, considering their current situation with their

health; and were expecting the paper form to have been sufficient. Many others were quite cynical and expected they would be required to go regardless of what information was on their paper form.

Key comments:

“...just a bit depressed and worried, very worried [about the outcome]...they could have had a conversation about what it would entail, they could have let me know, if I didn't get passed fit for work what would happen, or if I got not fit for work what would happen...they didn't go into detail and you want to know.” (F, 55-64, Schizophrenia)

“I suppose they weren't too upsetting the questions but...all the time I was thinking 'I might not get it'...I was worrying about it. And all the time while we were waiting for the result to come through, like I were hoping once we sent the form in, we wouldn't have to go for a face to face, I thought form would be good enough and I was a bit disappointed when I had to go for a face to face. If you saw how many tablets I take every day and I've been ill since I was 20...” (F, 65+, Bipolar)

5.3 Work Capability Assessment - Face to face assessment

Following the paper assessment, some people are invited to attend a face to face assessment as part of their ESA claim. These can take place at the Job Centre but at other locations also. The format is that of an interview, with an assessor who could be from any type of health and care / medical background (e.g. registered general nurse, doctor, and physiotherapist) who works for the company delivering the assessments – currently Maximus, previously Atos. When filling in the paper form, applicants are advised on the possibility they may have to attend an assessment in person; and are asked to provide details on when they couldn't attend and any special needs which need to be taken into consideration (such as travel and accessibility).

Location of the face to face assessment

For almost all of the participants we spoke to, travelling to a new or less than familiar location for the assessment worried them, and often had a negative effect on their mental health. Participants reported the locations are often difficult to get to even if you are able to drive and often worse if you are required to get there by public transport. Some had been reimbursed taxi fare costs but found it to be a struggle to claim these. Others felt they had to put in lots of effort to prepare in advance, worried a great deal as they knew it was coming for a while; but felt uncertain about where the location was going to be, so had to do a trial run. All of these concerns are set against the backdrop of worry that is highlighted at the end of the paper form reminding people of the penalties if a form is returned late and the fear of not receiving their benefits and therefore not having any money if the decision goes against them.

None of the participants engaged with for this research were offered the opportunity to have the assessment at a location of their choice (for example in a familiar location or own home) although some had heard of people who have been offered this. Some participants explained their assessments were not at their closest JCP, but somewhere else they have never been to or heard of. Participants also noted that although the paper form does state to get in touch with any special requirements, again it appears to be mainly physical accessibility that is taken into consideration rather than in relation to people with mental health conditions who may have limitations due to heightened anxiety or confusion.

From the perspective of some carers who had supported participants, a long wait in an unknown location was extremely unsuitable for someone with depression, anxiety and lack of confidence. A more familiar environment, at home or elsewhere, could help ease stress experienced during or before the meeting.

Key comments:

“We had to go to a special building, she didn’t give us any choice...I would have liked to do it at home. It was like offices, council kind of thing...worried about going there...an office I wasn’t used to that type of thing at all.” (F, 55-64, Schizophrenia)

“I think it would make you more relaxed in your own home rather than just a little tiny room, them staring at you, tapping on their computer, not really taking much notice of what you’re saying.” (M, 45-54, Bipolar)

Choice of someone to accompany

Participants were in the main pleased with the fact that on the invitation to the assessment, people were given the option to bring somebody along with them; even if this realisation was made after the event. Everyone we spoke to would have liked this or did have this, although some did not take anyone because they didn’t think they would need support, they didn’t have anyone who could go with them or did not realise this was an option at the time. This led to the suggestion that people should be advised to take someone with them, and in the event of not having anyone to attend with an individual, an advocate should be provided.

Some, particularly those who were speaking to us as relatives / carers who have supported people through the assessment process, felt that a second person makes scrutiny easier and also means someone is able to monitor what the assessors are writing down. Other participants, who described themselves as being more trusting, chose not to take anyone; at appeal they saw a copy of their report and saw it was nothing like their own recollection of what was said – so in retrospect would have liked to have had someone there with them at the first assessment. Those with particularly strong views on the subject saw the absence of an advocate in the assessment as an infringement of their human rights; another explained that the person they had taken with them had been advised not to speak. Participants in the group recalled the disability advocates which used to be available through JCP but funding was thought to have been cut for these.

Key comments:

“I was yeah [given the option for someone to accompany during F2F assessment] but I haven’t got anybody...I’d like to have had the choice, if I’d have had a mental health worker at the time I would have took them I think, but again they’ve got such big caseloads and so little time to do things, but maybe that’s something they could look into in the future, somebody set-up just to escort people to give them impartial support if people need it.” (F, 45-54, Bipolar)

“If that option [bringing someone to accompany] was available I wasn’t made aware of it.” (M, 45-54, Anxiety Disorder)

Talking about condition with assessor

Although it was acknowledged that discussing their condition with a complete stranger was difficult, and in some cases far too difficult for them to understand why they are asked to discuss it repeatedly for different assessment types, many noted that if the right person undertakes the assessment then this would be a less daunting prospect.

Those who had been through a number of WCAs mentioned that over the years the face to face assessors have improved in terms of how they are during the assessment; but recall the very upsetting situations they have been in for some past assessments. For some who have recently experienced the face to face assessment for the first time, they found it to be dehumanising and left feeling very low. This wasn't the case for all, and some participants who had accompanied people to assessments had felt that some were not unpleasant experiences – from their perspective as second person there.

The main issues raised by participants about talking to face to face assessors were:

- A lack of empathy or even sympathy for someone's situation
- A lack of knowledge, skills or qualifications in terms of mental health
- Neutrality of the assessor came across as uncaring
- A lack of guidance or probing / prompting from the assessor resulted in short, general responses from the person as didn't know how to answer
- Difficulty in talking openly, with insight and accuracy about one's own mental health condition, while unwell

Key comments:

“Cos everything is written in my records and that I don't know why they have to go over and over again repeat it.” (F, 45-54, Depression)

“It was hard to share...I just thought I'm gonna be really honest and I think the day I did go I was just so depressed, it was a real struggle, I just couldn't have cared either way I don't think. So she got me on a really bad day. So I don't know if that made a difference but it was a regular day for me where I was particularly troubled by my mental health. Yes of course it's hard talking to a total stranger, getting them to approve whatever it is £74 a week its just awful its like begging to me.” (F, 45-54, Bipolar)

“Logistically it's very difficult for people who don't have carers and support workers or job centres up the road, it's hard if you are limited in your support to get all this together to make a good enough case to be believed.” (F, 45-54, Bipolar)

“The problem with it for me was you're so disgusted with yourself, you're so disappointed with yourself...as time goes by you realise what a bad place you've been in. Expressing that to another person is very difficult.” (M, 45-54, Depression)

“This process has caused her ill health at the moment. She's back to square 1 all because of the massive process” (Carer of - F, 25-34, Bipolar Disorder & Anxiety Disorder)

Assessor's knowledge and understanding of mental health

Having an assessor that has specific skills or qualifications relating to mental health conditions was considered by all participants as a crucial aspect of the assessment process, as this can make a huge difference to how someone feels about discussing their mental health condition.

None of the participants who took part in the discussion group or depth interviews could recall ever having a face to face assessment completed by a professional with a special interest or training in mental health. Some participants indicated they had come across assessors with some basic understanding of the difficulties someone with a severe mental health condition faces – but these tended to be people who had been through numerous assessments and more recently had been assigned an empathetic assessor. Although having this was seen as a rarity, as the majority of people engaged with had not experienced any treatment by their assessor thought to be particular to applicants with mental health conditions.

The impact of assessors lacking in these skills on participants' whole assessment experience cannot be understated; applicants with difficulties relating to their mental health do not feel their conditions are understood – especially in comparison to physical health conditions, which people with both of these diagnoses experienced first-hand.

Almost all participants gave at least one of the following themes as being issues for them when reflecting on their experiences of the face to face assessment:

- **Fears of the unknown** – participants were provided with very little information ahead of their assessments, particularly with regards to what they should expect to happen on the day. This understandably led to anxiety and worry for participants ahead of the interview, meaning they often went into the assessment nervous which affected their ability to respond fully to the questions asked. The face to face assessment itself did not seem supportive of their recovery or improved wellbeing.
- **Perceptions that the assessors have little specialist training in mental health and the helpful role of supporting documentation from clinicians to counteract this** – as mentioned above, this was one of the major points about the assessments that participants found difficult to fathom and get past. Almost all participants were of the belief that without a specific understanding of mental health a fair assessment of an individual's mental health state and their ability to work could not be undertaken. For some participants, bringing along expert clinical documentation had helped to bypass the assessor's lack of knowledge, as the assessor then took the participant's condition more seriously.
- **Little or no respect for mental health conditions and associated difficulties** – largely considered a product of the above issue in that without training in mental health, assessors (through no malicious intent) are not fully equipped to understand and deal with all the aspects of mental health conditions – which has a negative effect for both parties as things can easily be misinterpreted. Participants gave some specific examples of where misinterpretation of what mental health conditions (in general, as it is noted that symptoms can be unique even amongst those with the same diagnosis) can mean for those experiencing them. Participants spoke about feeling judged and misunderstood by assessors on these following aspects:
 - **Being well-spoken** – some participants felt this counted against them in the face to face interview as the assessor assumed because they were able to speak eloquently they couldn't be ill to the degree they claim to be.

- **Making an effort to dress smartly** – participants mentioned that for their first assessment they tried hard to be well turned out, but felt this also wasn't in line with the assessors' perceptions of people with mental health conditions. So in subsequent assessments they ensured they made less effort with the way they looked
- **Concerns over being perceived as a malingerer** – conversely to the above points, participants who also have physical health conditions discussed how they worried about going into the interview with their walking aids, or trying to convey their physical pain for fear of it being classed as malingering. This was a particular concern for those still waiting for a diagnosis.

A minority of participants did have positive things to say about the assessors they met with, with some who had been through the process a number of years ago; recognising the progressive improvements the DWP and Job Centres have made to the process. These participants acknowledged that assessors had improved in terms of their manner and empathy, but there is still room for further change.

Key comments:

“Had to go for this assessment, put so much effort in made sure I looked nice, make sure I'm in a good mood, and oh god it was horrible, he didn't care what I said unless it was yes or no to his questions...I've got copies of all his notes and stuff...the fact that I'd dressed well...the fact that I talk eloquently, that was a negative thing...some of the stuff was completely the opposite to what I said.” (F, 25-34, BPD)

“She didn't really show it [respect for condition] either way...well I suppose that's how they have to be. Although if she'd have sort of made me feel that I weren't saying enough, maybe I would have said more.” (F, 65+, Bipolar)

“Absolutely not, nowhere near enough [assessors with mental health skills/knowledge], that really needs to change. They need to have more than just a basic awareness, or recruit different specialists...draft a worker in with a specialism of mental health. You wouldn't see a doctor for your back that was a specialist in eyes or something would you? It's no different.” (F, 45-54, Bipolar)

“Maybe it has improved, but I had one experience in the very beginning and it was just disgraceful really. Bu this last lady that I saw, she appeared on the surface to be empathetic and aware of my difficulties – but that is not a regular occurrence, in my experience that's a rarity.” (F, 45-54, Bipolar)

“The assessment that definitely should be a doctor or someone who is qualified in whatever is wrong with you. Because mental health especially it's such a big spectrum, it's not as cut and dried as you don't have a leg or something.” (F, 25-34, BPD)

5.4 Decisions following the Work Capability Assessment

Following the completion of the paper and face to face assessments, the assessor who undertook the face to face interview writes their report and puts forward a recommendation as to which group the claimant should be placed in. The recommendation is reviewed by the Department for Work and Pensions who then inform the claimant of the decision. This is usually done via what is called a decision letter.

Timing

Although respondents felt they were not informed about what happens next following the face to face assessment, the time taken to receive the decision was just accepted as another anxiety-inducing part of the whole process, with detrimental impacts on the wellbeing of some. The majority of participants didn't feel they waited a particularly long period of time to receive their decision letter, but any wait at all tended to cause undue stress for people.

The minority of participants who felt they did end up waiting far too long for the decision explained it was difficult to have the decision looming over them each day; especially as the wording in the paper form and in the invitation to the assessment was perceived as quite threatening – all the time people are concerned they are going to lose their benefit and as such have no money on which to live.

Decision and explanation following assessment

Within this qualitative sample, it was rare to encounter individuals who had been satisfied with the first decision they received following their assessment; they remained confused about being awarded no or very few points, when their own perception of their illness and the medical evidence suggested to them they should qualify for the ESA support. For some, the immediate fear of losing financial support affected their wellbeing.

Key comments:

“Then of course there is the threat of losing your house, which is immediate...its not just a downward spiral it's a drop, you had something there that's supporting you, and you're trying to do things to help yourself to get back into work or voluntary work...then its gone, and you're in a very dark place...then I ended up walking into the river...it's [the impact] immediate.” (M, 45-54, severe depression)

“I had someone from [charity]...go through everything for me because they literally stopped everything then and there, and then wanted money back so I had to give money back that I didn't have to start with.” (M, 45-54, severe depression)

Appealing the decision

Several participants had chosen to appeal, after not being satisfied with an original decision. The role of evidence seemed to be pivotal in preparing for an appeal. On the one hand, there was some cynicism about whether any new evidence would be acknowledged or a decision changed. On the other, some participants invested time and effort into gathering the best evidence dossier they could including notes from key workers and clinicians.

The appeal process seemed to be lengthy for most (12 months or more) and to culminate in an extremely short meeting of a few minutes, at which point a different decision from the original one would be made – to join the ESA Support Group. To add to the arduous duration of the appeal process, the experience of attending the appeal could itself be intimidating. This ongoing stress often had a damaging effect on wellbeing and in at least one case resulted in a participant being prescribed with increased doses of anti-psychotic drugs to cope.

“I don’t know how but it [appeal] went my way in the end, and they found out that I got 17, 18 points and that really and truly, according to the doctors and psychologists it should never have happened in the first place, I should never have been evaluated in that way.” (M, 45-54, severe depression)

“That appeal was a nightmare and it’s broken her. It’s really broken her and it’ll take two years to get right- it’s always two years...” (Carer of - F, 25-34, Bipolar Disorder & Anxiety Disorder)

5.5 Work and health

As mentioned briefly in the introduction, the research also had a secondary focus on the link between work and health; looking into the support people may or may not receive to help them stay in or return to work after a period of illness. Given the Government’s ambition to reduce the disability employment, gaining understanding of the relationship between work and health for people affected by mental illness was felt to be an important aspect of the overall aim of this project.

It is also recognised that people with mental health conditions experience difficulties in disclosing their illness to employers, and that they often require specialist report to be supported to stay in work or return to work. In this section, the main themes around work and mental health conditions are explored.

Disclosing mental health when applying for a job

Fears around informing potential employers about their mental health conditions were clear, and for some these fears had been realised and evidence of casual discrimination was found.

Many felt that by telling a prospective employer about their mental health condition, it would affect their ability to get a job. For some this was just a theory which they hadn’t tested out yet as they had not had the opportunity since becoming ill to apply for new jobs, but for others; they had experienced discrimination in not being successful in their application or even having a job offer retracted after disclosing the condition. Another example was given regarding references; one participant had been told by their new employer that their previous manager had refused to give them a reference – because of the amount of time taken off when unwell. Although the new employer did not penalise the participant for this, it is still discrimination and negatively impacted the person’s confidence and wellbeing.

One individual had successfully applied for a part-time job, without disclosing her condition; she was currently able to cope with the demands of the job and fears she would not have been successful had she disclosed.

Participants wanted clarification over whether they would be penalised if they were to disclose their conditions on applications or at interview. Despite discrimination in this way being illegal, the experience of participants suggests that the law is not being adhered to in practice.

Experiences of becoming unwell whilst in employment

Almost all participants could recall at least one occasion since their symptoms began to affect them where they had been unwell whilst in employment – with the exception of those who were undertaking unpaid caring roles, or who had experienced the symptoms whilst already not in work. Participants have a great desire to work and to have a career, but due to the impact of

their conditions, participants had been fired, gone off sick and never returned or handed their notice in. Participants explained the main issues associated with becoming unwell from their mental health conditions whilst in employment, which included:

- **Anxiety over explaining the reason for absence to the employer** – many spoke about how employers were kept unaware of why participants were unable to go into work because of an undiagnosed mental health condition, especially when people were younger and without the knowledge of their illness. This was said to be less often the case if the employer had shown themselves to be understanding about mental health, but it could still be difficult for people to open up about why they could not attend work. Participants wanted to feel safe in the knowledge that they could be as open as they feel comfortable with when not feeling well.
- **Not wanting employers to perceive absence from work due to mental ill health as necessarily a big issue** – the variations and complexities of mental health can sometimes result in a person needing just one or two days off work to feel better. Long periods of absence from work could have detrimental effects on aspects of participants' well being too, so they did not want employers to always assume the worst and that time off for a person with mental ill health would be a big issue over a long period of time.

Key comments:

“No I don't think I would, cos sometimes it goes against you, they don't really like that type of thing the bosses...in my experience I haven't had much joy in getting a job cos I've told them I've been Schizophrenic.” (F, 55-64, Schizophrenia)

“I continued working as a [nurse] for the rest of my life basically, got diagnosed...still managed to work, I have had time off when I've been unwell obviously I've had to and I reduced my hours to part time about 10 years ago, so I've always worked.” (F, 45-54, Bipolar)

Limited support when unwell whilst in employment

For many participants, their experience of support from employers when experiencing periods of mental ill health had been limited. Some felt that, initially, employers had taken on board their conditions and followed whatever procedures were in place to support them; but this only ever last a short time, eventually petering off and resulting in the employees feeling as though their only choice was to resign or continue to be off sick when the employer's support waned or when employers imposed increased workloads.

Some mentioned noticing a difference between the treatment they'd received over their mental and physical health; noting that it's easier to explain 'what's wrong' when you have something physical to show or tell them about. Correspondingly, employers sometimes showed more understanding of physical conditions.

For those recalling working many years ago, they didn't feel able to speak to their employer to let them know about any diagnosis or the fact they needed time off work because of it. This was thought to be down to employers having less understanding 20 years ago, although participants recalling more recent events still felt uneasy about disclosing their mental health conditions over fear of discrimination.

Overall, participants had not had positive experiences with being supported to stay in work. Participants were quick to empathise with employers, stating they understood, from a business perspective, that having to make adaptations and changes for people with mental health conditions wasn't cost effective – with participants discussing the implications on businesses if they were able to be more flexible with working hours and/or patterns; but the empathy didn't appear to be reciprocated by the employer.

Key comments:

“It's on my sick note – bipolar – but I've not been in a job where I've been actively supported, or said 'is there anything else we can do without the need for you to go off sick? Is there any adjustments we can make?' I've never experienced that no.” (F, 45-54, Bipolar)

“The thing that was missing was compassion...I was dealt with in a terrible fashion...I would say they [school] saw it [mental illness] as a weakness.” (M, 45-54, Depression)

“I agreed to go in and see them and they'd put in place all the different things - they were gonna be flexible on...flexible on me hours...longer break...which worked for about the first three days...then managers were just constantly on my back.” (M, 45-54, Bipolar)

“My supervisor was really good, she was understanding about depression and stuff, but the actual person that was in charge...she was really cold...and when I'd been off I came back...I saw their occupational therapist...that was good in a way as he was a qualified person...but then when I did get depressed and I needed time off... time off wasn't okay with them...” (F, 25-34, BPD)

Positive support when unwell whilst in employment

Where employers had been considerate and understanding of the participants' conditions, participants recalled being able to openly say to their manager that they wouldn't be coming in that day without being probed further as to why. This approach was rare and tended to encourage participants to remain engaged at work and to stay happy and motivated.

“[Previous manager] He was amazing I didn't even have to tell him...he was just so understanding...he went out of his way to make things okay for me...if I was having a bad-ish day but I feel like you know I can cope with it because my boss is there and if I feel bad I can go home, it's more likely to make me want to go to work rather than if I know my boss is not going to be caring or understanding then it makes me less likely to want to go to work.” (F, 25-34, BPD)

“[You] try and do your best but sometimes you just can't, so they [previous employer] allowed me to take some time out and come back again and pick up...some of the patrons who used the restaurant kinda guessed it too...I made some really good friends from that.” (M, 45-54, severe depression)

Positive or negative impact of work on mental health

A few participants had conditions so severe that they cannot at this moment see themselves working - either because they feel they wouldn't be taken on by an employer or they wouldn't be able to commit to a work routine due to their symptoms.

Almost all participants stressed the positive effect working can have on their mental health, if supported correctly. The main positive effects were said to be around self-confidence, dignity,

self-worth and just doing everyday 'normal' things like everyone else. If not supported in the right way or at all, participants could quickly find themselves in situations which lead to unemployment.

Some participants discussed their more negative experiences of being in employment and how these can affect their mental health. A number experienced bullying in the workplace, which of course eroded self-confidence, exacerbated their existing mental health conditions and made their conditions more difficult to self-manage.

Key comments:

"I would love to get a job in a café, I'm used to it you see, and I would love the support from people, support from the boss and understanding – which I haven't got in previous jobs...I'd love to go back to work cos it would make me feel more like in a normal world – know what I mean? Something to do away from all the doctors, psychiatrists, nurses just back to my job, something to get paid for, to make me feel...more human again...everyday life I am longing for." (F, 55-64, Schizophrenia)

"I want to work, I value work not just for the money but the last five years I haven't worked it's had a really severe impact on how I feel mentally, because I'm losing my confidence." (F, 45-54, Bipolar)

Suggestions for improvements to support in the workplace

Participants gave some suggestions for how they can be supported to remain in their jobs whilst experiencing ill health:

- Supportive colleagues who keep in touch even when off work
- Empathetic management who see the value in keeping members of staff working for them
- Discreet approach to dealing with periods of absence
- Support from a union

As mentioned above, participants felt it is important to look at an employer's side of things: they understood that supporting people with mental health conditions can take time, it can take away from productivity and that other colleagues may find it frustrating or unfair. Participants felt that employers may need some specific training and incentives in order to help them support people like them well.

Key comments:

"Just somebody in the workplace that is not going to judge you, bearing in mind that I have worked in mental health all my life; you'd think my managers would be perfectly placed to offer that kind of support it just baffles me." (F, 45-54, Bipolar)

"Just somebody to be aware and maybe have some protocols and practices in place...someone to say 'let's think about what we could do, maybe have one day off to get your head together a bit' and that's it really...I don't want all singing all dancing, I just want someone to say 'it doesn't matter, let's not make it into a massive thing, let's see if we can work round it, keep everybody safe and well' obviously you can't be at work if you are really too unwell but there are measures that can keep people in work when they're perhaps not in crisis." (F, 45-54, Bipolar)

5.6 Seeking support

For people with mental health conditions, being offered appropriate and timely medical and psychological support to assist with the symptoms of their illness is crucial to their ability to begin to manage their condition. The medical support received can have an impact on an individual's ability to stay in work or get back into employment and is therefore relevant to this discussion.

Medical support for people experiencing mental health difficulties can come in many different forms, and may also be dependent on where they live in the UK. This section discusses what support participants have accessed on their journey, both what has been helpful and not so helpful and how they have found accessing such support.

Some of the participants in the age categories of 45+ recalled finding the experience of becoming ill and subsequent treatment overwhelming, with stigma affecting their ability to come to terms with their conditions. Help and support was difficult to get, and for those with children life was particularly challenging in terms of working and finances. These participants continued to work although they were unwell, as much as their benefit allowed. Many people we spoke to in these age categories who have had their diagnosis for many years, indicated they had been discharged from their mental health services and do not receive support through them currently. Others had moved house and seen their support change, some for better, but also some for worse; indicating that participants had some experiences of inconsistency when it comes to receive in support for issues relating to their mental health conditions.

What was clear from the conversations with participants for this research was the appreciation felt when a service helps them in a way which positively influences their life; particularly with regards to employment which is seen by many as a big part of living a more 'normal life'. Therefore the value of people with mental health conditions accessing healthcare services as a way of helping them take steps towards work should not be understated, and people do like having the knowledge they can access support if they needed it.

Key comments:

"What happens here is you go to the Primary Care Services, they assess you, change your medication and then discharge you – they haven't got the facilities to keep you on the case load...before I moved I had a psychiatrist, a mental health worker and I was in supported housing! So I was very fortunate, and I'm really feeling it now."

"Down here [new home town] they wouldn't even keep me on the books [mental health team]." (F, 65+, Bipolar)

"I think early intervention is one of the main things, and obviously that is very difficult to get...Theresa May keeps saying she's going to put money into it, yet all these different places there is to go who help you – she's not giving them any funding." (F, 65+, Bipolar)

Some suggestions were offered about improving access to support for mental health conditions. Themes included:

- A more human, less formal approach
- A holistic approach that does not just focus on deficits and medication needed
- Early intervention
- Understanding GPs

- Joined up thinking across all the relevant sectors

5.7 ESA assessment categories

The WCA assessment's eventual aim is to determine which of three assessment categories the claimant, based on the paper form, interview and medical evidence; should be placed in. Claimants could be recommended for placement in one of the following categories:

- 1) Fit to work
- 2) ESA Support group
- 3) Work Related Activity Group (WRAG)

Depending on the category they are placed in, claimants may be required to undertake certain activities or none at all. If people are not satisfied with their decision they can appeal – as discussed above. The category people are placed in also has an impact on the level of financial support they receive. The following sections discuss the findings from participants who spoke about their experiences of being categorised in any of the three groups.

Fit to work – the work programme

All but one of the participants we spoke to who were categorised as being fit for work disagreed with the decision. The disagreement was in the main based on their current situation regarding their condition(s), but also the worry about applying for jobs with the threat of being sanctioned if they don't meet their personal targets. This was especially the case for one participant found fit for work who is close to retirement age following a lengthy period of time spent caring for loved ones and without digital literacy skills or much formal employment experience. This individual explained they are now appealing the decision, after meeting their work coach and being told to undertake compulsory maths and English courses; along with drafting a CV using the computer – a list of tasks which caused great anxiety for the participant due to not having any experience in these areas.

The one participant who was pleased to be found fit for work because of their desire to get into part time work; soon found that the support available to her on the work programme was almost non-existent – meaning they had no support in finding work even though they had a diagnosis of a severe mental health condition and would require specialist support to work again. This still impacts on the individual now in terms of their confidence and attitude towards finding work – they don't feel they will be employed by anyone again because of their mental health condition.

Key comments:

“I rung the job centre up and got an appointment, I couldn't believe what they were saying to me, that I had to go out to work and it was a lady that I saw there but the person I was supposed to see wasn't there so I have got to go back. I've got to somehow learn how to use a computer...and I've never been in this situation before...and they don't seem to be sympathetic...they're going to learn me to do a CV at 62 years old, if I don't look for any job they'll stop my benefit.” (F, 55-64, depression)

“I think it's [Work Programme] just a one size fits all, and you can't put 50 people with 50 different mental illnesses in a room...there needs to be clear pathways for [those with mental health conditions who want to work]...I want to work, I'm desperate to work, but I can't get a job because I disclose my own mental health on the medical forms, so it's turned round and bitten me in the face...if they're going

to say ‘this is back to work support’ then they need to make it back to work individual support.” (F, 45-54, Bipolar)

ESA support group

Almost all of the participants had been in the ESA support group in the past or have been categorised as such following their most recent assessment or appeal. As none of these participants had received any ‘support’, the general consensus was that the word ‘support’ related to financial support rather than any other type of help. This was the group that many people felt they should be in, as they felt too unwell to work which was their motivating factor for applying for the benefit.

When discussing whether more support would be useful in this group, and also whether this could be voluntary or mandatory; participants were extremely interested in the idea of receiving support following being placed in this group – however it would need to be considered on an individual basis. This was because the idea of being supported into work by someone who understands mental health would be a positive step in the right direction in terms of helping people with mental health conditions get the right job not just any job; like what may happen on the Work Programme.

Participants with experience of being in this category explained how being placed in this group not only puts their financial worries on hold for at least one year; it can have a very positive impact on their general wellbeing, allowing time to become more healthy, to undertake part time or voluntary work – as the worry over a job and money whilst unwell is no longer there.

Some people raised concerns that any steps they take towards working (volunteer work, courses) could affect their benefits. The muddy waters around this issue can result in people not taking opportunities which may positively impact their condition and their lives as a whole.

Key comments:

“Basically once they say you are in the support group, the support group is there to guarantee that you won’t get that [assessment] for a certain length of time and at least you can focus and do things and they can recognise you’re doing charity stuff... But it’s not a support group to get mental health support.” (M, 45-54, severe depression)

“I’m told you can do up to 15 hours of paid work and still be in that [support group]...if that is not possible, I’d rather just have my support net of benefits rather than break free from that and everything falls into chaos money-wise...it would be good having help and advice...if you do wanna work or do voluntary work, that there is someone there to support you and make sure that’s okay.” (F, 25-34, BPD)

Work Related Activity Group (WRAG)

This was the category that those in the sample were least likely to have experience of being placed in. Some had perceptions of it, that you receive help getting back into work – but it isn’t as intensive as the work programme. The minority that had been referred onto this group in the past, indicated that they had not undertaken any work related activities whilst in this category – apart from an initial assessment and 8-weekly meetings.

Those who had been placed in WRAG, didn't have many positive aspects to discuss. Some noted that the advisor they were placed with didn't try to encourage any work related activities (such as courses or activities); and as such they felt attending was just them and the DWP going through the motions which had little to no positive impact on their employment status or their mental health. Specialist advisors, although the title suggests that there may be some special area of expertise, were not felt to have any skills or knowledge in the area of mental health – which was seen as a real negative factor (as with the face to face assessors) impacting on their wellbeing and job prospects when situations aren't handled in the right way. For example, one participant was told to move away from their original career, another to only search for certain work; on the basis of their mental health diagnoses.

Key comments:

“I now know, I didn't then, that it is the Work Related Activity Group, but basically for me it was just going to the Job Centre to see a – inverted commas – specialist advisor, who was really lovely and didn't bother me much, but he didn't give me any additional support either, so he kind of left me alone which was good, cos you don't need the worry of applying for however many jobs a week like you have to do on JSA but he was like ‘oh just come and see me in 8 weeks’ that was the support I received! And the deficits across the country are huge, some have really good job centre staff, some don't.” (F, 45-54, Bipolar)

“He didn't encourage me to you know perhaps ‘ooo let's look at what courses are available that you could maybe think about doing’. So I was kind of...for me at the time it was good, because he wasn't badgering me, but at the time I can't actually say that I got any additional support...just ticking a box for him.” (F, 45-54, Bipolar)

5.8 Work coaches

A minority of participants had some recent experience at the job centre and could comment on their experiences. The job centre was perceived as inaccessible as all telephone calls were routed nationally; a more personalised, keyworker approach would have been preferred. Some people felt de-humanised by their unsympathetic treatment at the job centre.

Many participants had little recent experiences of work coaches but were able to talk about the role of work coach in a hypothetical way. There was a perception that work coaches may be better informed about mental health than in the past; perhaps through more exposure to people with mental health conditions, or via ‘mental health first aid training’ that was mentioned by one carer. What participants really hoped for from work coaches was to be treated “nicely” and for the support to be personalised, tailored to the aspirations of the individual.

Key comments:

“When you go to the Jobcentre...you get followed by the security guards, they look at you as if you are slime, they literally man handle you, frog marched...demanding to know why you are here...even through it's private.” (M, 45-54, severe depression)

5.9 Suggestions / final comments

Participants were invited for their final suggestions about the WCA or more generally about support for those with mental health conditions.

The majority of comments centred on improved training and awareness of mental health conditions, coupled with a personalised approach, among those drafting the WCA forms, assessing the forms and carrying out face to face assessments. Stress could be removed from WCA claimants by assessors gathering medical evidence directly from healthcare professionals and by encouraging / allowing carers or supporters to take an active role.

Key comments:

“Well I think the paper bit, it’s not gathering the evidence yourself – a simple remedy for that would be giving consent and DWP write to your doctor – taking the pressure off you when you’re not well...” F, 45-54, Bipolar)

“On the face to face, it would be more than a basic awareness of mental illness, because it’s so dramatically different, I think for me, because I’ve had it so long and I present fairly well...people get the wrong end of the stick and think I’m okay, but that’s a personal thing I try very hard to keep well..” (F, 45-54, Bipolar)

“I think each appointment - they should know before the person steps in whether it’s mental health. It should be a lot more geared towards people with mental health issues in either questions or time allowed for that person to get it across.” (M, 45-54, Anxiety Disorder)

“Treat people from a psychological and social viewpoint. Otherwise you are treating the symptoms and not the cause...Treat people holistically as a person” (M, 45-54, Depression)

6. Conclusions

The below conclusions are based on – and driven by – the comments and views put forward by the participants engaged with during the course of the research

Conclusion One – WCA: The Form

For many, the current paper assessment form does not adequately allow them to explain the impact of their mental health conditions on day to day life or on the possibility of working. If the paper assessment form is to be retained in any future assessments, then there should be a **separate form** (or section) available **for people with mental health conditions**. Expert clinical input should help frame the questions on such a form. Clear guidance should be provided for those undergoing repeat assessments about whether only new information is to be included or whether information from previous forms should be re-stated alongside new information. It would be preferable for claimants to avoid being asked to repeat information that has not changed between assessments, as it can cause distress.

Conclusion Two – Support for WCA Claimants

Claimants should be **encouraged and enabled to take up support** from a friend, family member or perhaps an advocate via a local voluntary sector group. Some individuals will also appreciate being signposted towards self-help groups or virtual forums and sources of advice. Support is beneficial at both paper and face-to-face stages of the WCA assessment, yet does not tend to be taken up so readily when claimants are taking part in the WCA process for the first time. Later, repeat, claimants see the value of support and believe it results in an outcome that is closer to their expectations and which is more realistic about their mental health illness.

Conclusion Three – WCA: Medical Evidence

Claimants found it extremely and unnecessarily burdensome to have to locate and reproduce medical evidence, such as medication, for the form when this information already existed in medical notes (and notes from other professionals). They believed that (with consent) the **WCA assessors** should be able to **access the relevant, accurate, up to date medical evidence directly** from the health care professionals concerned. This burden was not only felt in a practical sense, but also emotionally; and this should be considered as a reason for not placing the onus on the claimant to gather the evidence.

Conclusion Four – WCA: The Face-to-Face Assessment

The face-to-face assessment was seen by many as a form of ‘medical’. As such, **assessors should have mental health skills, qualifications and experience**. A generic clinician serving as an assessor, such as physiotherapist or nurse, was not good enough when assessing someone with severe or complex mental health conditions. Participants also felt quite strongly that people asked to attend a face-to-face assessment should be **advised to take someone with them** (rather than offered the option). It is also important to recognise that not everyone will have someone they can ask to go along with them, so advocates (possibly volunteers) should be provided in these cases. Participants noted feeling **dehumanised by the assessment process**, some change is therefore required in terms of how the assessments are discussed with the claimants, how they are treated when they attend assessments and also the assessor’s ability to empathise with a claimant’s situation.

Conclusion Five – WCA: Appeals

Appeals are experienced as lengthy and stressful, although they do often result in a different decision to be placed in the ESA support group. Participants wondered why appeals are often able to come to what appear to them “*sensible*” decisions within a few minutes of an appeal hearing starting. If there are **elements of the appeals process** that are contributing to these better informed decisions, it could be considered to **incorporate those features in WCA process in the earlier stages**. This could perhaps be due to a greater amount of evidence allowed or invited for submission on appeal, someone with different skills making the decision on appeal, or other factors.

Conclusion Six – Support at Work

Support at work for people with mental health conditions does not appear to be consistent. Participants feel that individuals with mental health conditions would benefit from more clarity about their rights at work. It was acknowledged that **employers could be supported with funding and training to provide better support** in these cases. One major factor which should be considered when considering what support a person with a mental health condition might require would be **cognitive impairment**. Inconsistencies in a person’s cognitive abilities can really impact their everyday and working life; it is important for employment support for people with mental health conditions takes this into account as any support is likely to be needed long-term.

Conclusion Seven – Support to Move into Work

People with mental health conditions are open to receiving **support aimed at moving into work**, although they want this to be **on their own terms** so that their **current health can be taken into account**. They would like work coaches to be trained in understanding the impact of mental health conditions and for claimants to be able to take on voluntary or part time work without fear of sanctions. Again, the impact of **cognitive impairment** in moving back into work should be considered by all those involved with people’s employment activities. Not being able to complete daily tasks will have an effect on their ability to look for work, or undertake other employment related activities.

7. Appendix – discussion guide



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Rethink Mental Illness – Work, Health & Disability event

Discussion Guide / event format

Proposed format of afternoon:

12.30-1pm: Qa and Rethink Mental Illness meet at venue to set-up tables and refreshments

1.15pm – 1.35pm: VP and JB welcome attendees at main entrance to show people in to the room and allocated

1.35pm – 1.45pm: JM to introduce the event and answer any questions

1.45pm: Discussions start

2.30pm – 2.40pm: Break

2.40pm – 3.20pm: Discussions continue

3.20pm – 3.30pm: Round up discussions and hand out incentives

3.30pm – 3.40pm: JM close the event and offer participants to stay and chat / more refreshments

3.40pm – 4pm: Chat/refreshments/end of event

Qa introduction – 2 mins

My name is xx and I work for Qa Research – an independent research company. Thank you for coming along today. Although Jonathan has given a great introduction as to the reasons behind and purpose of the event today, we just have a few things to go over before we get started, then we'll see if you have any questions before getting stuck into the discussion.

We have been asked by Rethink Mental Illness to discuss with you the process and your experiences of the DWP's Work Capability Assessments. At Qa, we do research for lots of charities, organisations and councils to find out what users of those services think and to find out if things can be improved at all. Although some representatives from Rethink Mental Illness are here today, we are independent from Rethink Mental Illness and also from the DWP; we would like you to feel you can be as open and honest about the service as you feel comfortable with. Jonathan is here to answer any questions which we may not be able to, so please feel free to stay on after the discussions to chat with him.

We are going to talk a little bit about ourselves to get us started and get to know one another a little if that is okay with everyone? Then we will discuss your experiences – please be as open as you feel comfortable with. We have pens and post it notes if you would rather jot down some thoughts than speak out loud.

All of this data we collect will go towards writing a report for Rethink Mental Illness, which they will then use to go towards their contribution to the Government's consultation on Disability and Work the potential reform of Work Capability Assessments, therefore your views are really important to us and to Rethink Mental Illness. The report will include quotes, but these will all be



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reported on anonymously – no one will know what you have said and nobody's name will be used.

The discussions will go on for a couple of hours, but we will have regular breaks for fresh air / toilet and if anyone needs to / wants to leave at any point that is fine. Because everything you say is important and I won't be able to write it all down, is it ok if I record the session? If not it is fine we can just make notes. The audio recording will stay with my company, Qa, and will not be shared with anyone else. Does anyone have any questions before we begin?

Introductions - 5 mins

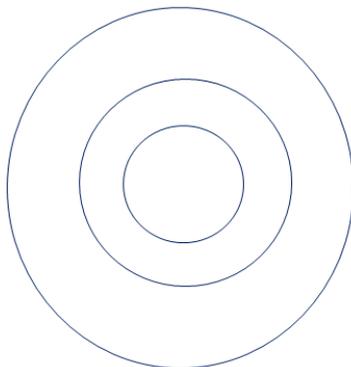
- Q1. Just to get us warmed up, let's go around the room and introduce ourselves, name, and what are the activities / hobbies you enjoy the most at the moment? If you don't have a hobby or activity you enjoy doing, tell us about something you used to do or what you'd like to start doing?**
- Q2. And, to find out a little more about you, we'd like to know who it is who tends to help you the most supporting you with your condition? This might be family, or friends, support workers, mental health professionals, your GP, or even a pet! It could be one person, it could be a lot of different people...just tell us as much as you feel comfortable with.**

ACTIVITY – Influencers Map

Give out post it pads + pens

People write down one name / job role per post-it (or shout out to moderator)

Stick post-it in one of circles – most helpful people in middle, fairly helpful in middle circle, slightly helpful on outside



Prompts:

- Are there friends or family who help?
- Are there people in the community who are good role models for you?
- Have people in organisations /groups/charities/ agencies helped?

Thanks, that's really useful / interesting.

Now, we are going to think about each stage of the Work Capability Assessment process. We will find out how it has been for you so far. We also have a few ideas from Rethink Mental Illness about what they feel would help WCA be better for people with mental health conditions. So we will find out what you

think of those ideas. We'll also ask you about your suggestions as you are the people who have the knowledge and experience of going through the WCAs.

Descriptors (questions asked in the paper assessment forms - ESA50) - 10 minutes

Context for moderator:

The mental health descriptors used in the paper assessment (ESA50 form) have been criticised for not properly reflecting the realities of living with a mental health condition, chiefly because they do not capture the fluctuations people experience.

Describing your condition

We'd like to know the extent to which the questions you were asked as part of your WCA allowed you to describe your condition...

- Q3. Thinking back to when you had your WCA and the paper form you filled in asked about your condition...did you feel the questions on the form allowed you to describe all the different aspects of your condition or conditions.**
- High & low mood (mania/depression), positive & negative symptoms, psychosis, anxiety, side effects of medications, what effect those different aspects of your condition can have on how you feel and the things you can do?
 - Could the questions have been asked in a different way or using different language to help you describe your condition as accurately as possible?
- Q4. What parts of their condition were you not able to describe within the questions the questions?**
- Did the questions asked give you the freedom to discuss your condition?
 - Were there any parts you didn't feel were captured by the questions?
- Q5. Were you able to answer questions about what impact your condition has on you?**
- ...or do you feel they could have been better answered by a mental health professional?
 - Do you have any suggestions for changes to the questions or the format of the questions?
- Q6. What information were you given on how your responses could affect the DWP's decision?**
- Were you given guidance on how to respond to questions? Either by the DWP, a professional or even a friend/family member?
 - Did you feel informed about what would happen next? E.g. when a decision was likely to be made?
 - Did you understand or have an idea of the likely outcome on the basis of what answers you gave?
 - Did you have any worries or concerns about the answers you gave to the questions?

ACTIVITY – scores for 'describing your condition' aspect of the WCA – each to add sticker to chosen score.

- Moderator can note any key words on the sheet alongside specific scores

Q16. Did you feel the assessor gave your condition respect and acknowledged the difficulties that you face as part of your condition?

- Did you feel the assessor was empathetic towards your condition or did they struggle to understand what you were telling them?

Q17. Did you talk to the assessor about their experience in speaking to people about their mental health conditions or did you not consider this / not feel up to /able to question them in this way?

- Did they offer to tell you a little bit about themselves and their experience in their introduction?
- If not would this have been something you would have liked?

ACTIVITY – scores for ‘face to face assessment’ aspect of the WCA – each to add sticker to chosen score.

- Moderator can note any key words on the sheet alongside specific scores

☹️	1	2	3	4	5	6	7	8	9	10	😊	

Decisions following the assessment – 5 mins

Q18. On giving you your decision following the application, did the DWP fully explain why they had given that decision?

- Did they mention / make reference to the medical evidence?
- Were you satisfied with the decision and feedback you received?
- Were you made aware how long you would have to wait for a decision?
- Did anyone have to follow up with DWP to get a response?
- Were there any hold ups in getting a decision?
- Were you informed of these?
- Were you told when these might be resolved?

BREAK – 10 mins

Other issues related to the WCAs – 10 mins

We are now going to think about reassessment...

Q19. If you needed a reassessment, what were your experiences of this?

- Did the process begin again immediately after you got the initial decision?
- Or did you feel you had enough time between the decision and the process starting again?
- Were you informed of the timeframes to expect?
- Were you happy with this amount of time?

Q20. Did you all get the decision you felt was correct?

- If not, why?

Q21. We also want to find out about your experiences, if any, of the appeals process. For those who were not happy with your decision did you feel informed enough to appeal the decision?

- If yes, did you feel you had the information and time required to appeal?

Q22. Did you have to go through the whole application process from the start?

- Were you well informed about this process? i.e. how long the appeal would take?

Q23. How did the waiting make you feel?

- Impact on your mental health?
- Impact on your physical health?
- Any other impact?

ACTIVITY – scores for ‘waiting for a decision’ aspect of the WCA – each to add sticker to chosen score.

- Moderator can note any key words on the sheet alongside specific scores

	1	2	3	4	5	6	7	8	9	10		
☹️												😊

Work and health – 10 mins

Context for moderator:

The government are also consulting on mental health in the workplace and are trying to find out what support people need to stay in work, and employers attitudes towards mental health.

Q24. When at work, could you tell us a little bit about your experiences of becoming unwell whilst at work?

- Were you supported to continue at work in a lesser capacity?
- Were you supported to take time off sick?
- Was it your choice or told/advised?
- Were you happy with the way your employer handled this? Did this impact how much time you had off?
- If had time off did your employer stay in touch? – Happy with the amount of contact you had with your employer?
- Did you have contact with work colleagues?

Q25. Did you disclose your mental health condition to your employer?

- Was this before you were employed? Did you feel unable to?
- Did they ask?
- Did you tell your employer it was your mental health condition that was making it difficult for you to work as usual? If not, what did they say?

- Q26. What was your employer's reaction and did they take steps to try and help you stay in work?**
- How did their reaction make you feel?
 - Did they state they had things in place to support employees specifically with mental health conditions?
- Q27. Did you feel your condition was given respect?**
- Q28. Have you experienced any particular support, help or initiatives that you feel had a positive impact on your mental health and ability to work?**
- If not, any ideas for what could be helpful?
 - Flexible working hours? Working from home? Supportive colleagues?
- Q29. Would you say working helps with your mental health or makes things worse?**
- If worse, why? What could have been done differently?
 - If better, why? What stands out as a positive in your experiences?
- Q30. When you need to seek medical support, how easy or difficult have you found this?**
- What support has been available to you? Support worker? CPN? CRISIS team?
 - Charity resources?
 - Self-led help such as CBT, DBT or support groups?
 - What could help with making Mental Health services more accessible?
 - Is the help you receive from the Healthcare Service useful in terms of aiding recovery and getting back to work?

Fit to work, Support Group, WRAG – discuss depending on the make-up of each group – 10 mins

As we have already discussed there are three categories people can be placed in following at Work Capability Assessment. We want to find out a bit more about your experiences of these groups.

- Q31. First of all I'd like to talk about the work programme (anyone declared fit to work). If you have been on the work programme, please can you tell us a little bit about your experiences, whether good or bad?**
- Do you feel the work programme is suitable for people with mental health conditions?
 - If you haven't been on the work programme what is your perception of it?
- Q32. For those in the support group, the Government are proposing to offer more assistance to people in this group...**
- Would you have liked to have been offered support or assistance once you were placed in the support group?
 - Did you feel able to look for work during this period or did you fear this may impact upon your status? (e.g. be declared fit to work before you were ready and face a reduction in your income?)

- Do you feel you would engage better with this assistance if it were voluntary or mandatory? **Notes for moderator:** *As things stand people in the Support Group can engage in the work programme (which people on Job Seekers Allowance have to – paid at a lower rate). But take up is very low, because we are concerned it will demonstrate that they are in fact fit to work, which could see them removed from the Support Group in the longer term. Suspensions from conversations is that if people in the Support Group were offered personalised support, with an accompanying guarantee that their financial support would not be affected, more people may take it up. Otherwise, the fear of losing out financially will prohibit people taking this up.*

Q33. For those of you in the WRAG programme- what have your experiences been?

- Has it been useful attending?
- What activities have you undertaken?
- Were you looking forward to it or worried about it?
- Did attending the group have a positive or negative effect on your mental health?
- Do you think the WRAG programme is suitable for people with mental health conditions?
- If applicable: did attending the group have a positive or negative effect on getting back into work?

Work Coaches – 5 mins

Context for moderators:

The Government's Green Paper proposes the WCA being used only to determine financial support, with Jobcentre work coaches deciding what work / steps towards it, each person has to take. We are concerned that this could see people who were previously in the Support Group (i.e. too unwell to work or move towards it) facing mandated actions from individuals who are inappropriately qualified to assess the impact of work on a person with a mental health problem.

We are going to finish off with a few questions on work coaches, so we are moving away from assessors now.

Q34. What is your relationship with your work coach?

- Good? Bad?
- What could improve the relationship?
- Have you had to ask for another work coach? – Have you ever been directed to a specific work coach by others in your position e.g. someone people feel is understanding / empathetic?

Q35. Did you work coach/coaches have an understanding of mental health?

- If not, what knowledge and skills were they missing?
- How do you think their knowledge and skills in terms of mental health could be improved?
- If yes, what was it about their knowledge/skills you felt was indicative of their understanding of mental health?
- Would another separate assessment by your coach be a good or a bad thing?
- Were you open about your mental health condition with your work coach? Why /why not?

Q36. What could encourage a better relationship with your work coach?

- Talking in a private room?
- Condition specific training for work coaches?

ACTIVITY – scores for ‘work coach’ aspect – each to add sticker to chosen score.

- Moderator can note any key words on the sheet alongside specific scores

Suggestions / final comments – 5 mins

Spider diagram exercise

Q47. We just want to finish on a positive note – so please take a post it note (or shout out to the moderator) and give us one thing you would like to see changed about the Work Capability Assessments that would help people like you get the most out of their assessment...

Thank and close