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*The views expressed in this consultation are those of the participants and authors they do not reflect or represent the views of the organisations identified above.*

## **ACKNOWLEDGEMENTS**

We would like to thank all of the participants of this consultation who came out on two bitterly cold afternoons in January 2013 to complete the questionnaire and take part in the focus groups.

## **BACKGROUND**

The Welfare Reform Act received Royal Assent on 8<sup>th</sup> March 2012 and legislates for the biggest change to the welfare system for over 60 years in the United Kingdom. The time leading up to introducing the Act was mired in controversy and debate, with campaigners highlighting some of the gross injustices as a result of the reforms:

Macmillan Cancer Support said around 7,000 cancer patients would be worse off, the Fawcett Society said the Government had failed to assess the impact on single mothers and The National Autistic Society decried the impact on disabled people.

(The Independent, 2012)

The Conservative/Liberal Democratic coalition government however argued that:

Reforming the benefit system aims to make it fairer, more affordable and better able to tackle poverty, worklessness and welfare dependency. We are committed to overhaul the benefit system to promote work and personal responsibility.

(Department for Work & Pensions, 2011)

## **AIMS**

The aim of this consultation was to examine the impact of the recent Con/LibDem coalition governments' welfare reforms on mental health service users who live in the North East of England

## **INTRODUCTION**

In the United Kingdom reform of the welfare system has begun in earnest with anecdotal evidence already emerging that highlights the increased vulnerability on many people including mental health service users. There has been an increase in the number of people claiming sickness related benefit in the last 30 years (Barnes et al. 2010), with 2.63 million currently receiving Incapacity Benefit (IB) (Lewis et al. 2013). This includes some mental health service users who are often subject to changes in disability policy and administrative procedures (Cook & Jonikas, 2002). A key controversial feature of the current reforms is the identification of people currently on IB who are deemed "fit for work". The coalition government is looking to reassess all those on IB with a new test;

the Work Capability Assessment (WCA) which measures a person's entitlement to Employment and Support Allowance (ESA). The WCA is causing fear among many mental health service users due to the nature of the testing procedure which is carried out by the healthcare firm Atos who have the responsibility of identifying the people on IB who are deemed "fit for work" (The Guardian, 2012). As recently as 22<sup>nd</sup> May 2013 two people with mental health problems won a legal challenge in the High Court claiming the WCA test would discriminate against them, with the judge stating the test puts people with a mental illness at a "substantial disadvantage" (BBC, 2013).

The North Tyneside Mental Health Forum (based in the North East of England) was set up by a Mental Health User Development Worker, Jane Noble in 2010, in response to Service Users (SU) who wanted somewhere they could attend for information and advice and the opportunity to mix with other SU. This need was identified over a period of 8 months which was necessary to network, meet SU and listen to what opportunities they would require. The early forum meetings offered largely 'peer support', advice and information. However, as the forum developed SU wanted to invite key note 'speakers' such as Welfare Rights Advisers, who could explain any relevant changes to provision and provide a platform for further discussion. The forum is now well established and has become a vehicle for the development worker to advocate on behalf of SU when developing new strategies and/or services with the Primary Care Trust, soon to become Clinical Commissioning Groups.

Andrew Clifton is a mental health nurse, researcher and Senior Lecturer. Together with Jane Noble, the idea was developed to collaborate on this consultation to examine the impact of changes to the welfare system to mental health service users in the North East of England. The collaboration was supported by Vicki Wilford (service user), researchers Jennifer Remnant and Joanna Reynolds and the many service users and carers who participated in the process.

## **METHODOLOGY**

We used a mixed methods design incorporating two key methods: use of a questionnaire and focus groups. Participants could choose to take part in one or both aspects of the consultation. The collaboration ensured shared facilitation of the consultation methods. Jane Noble and Vicki Wilford coordinated the questionnaire phase, and Andrew Clifton and Jane Noble led the focus groups. Purposeful sampling was adopted, inviting all service users who attend the North Tyneside Mental Health Forum. The number in attendance at Forum meetings fluctuates weekly (typically 10-15 attend). All service users had the opportunity to participate in the consultation, by augmenting the

consultation methods to ensure accessibility for all service users, e.g. providing postal questionnaires and additional focus group dates. 15 service users completed the questionnaire with the same number attending the focus group three weeks later.

Since the consultation was exploring service users' experiences and perspectives of changes in welfare provision, there was the potential for participants to become distressed. Service users completed the questionnaires independently during a scheduled Forum meeting, with their representative Jane Noble present who was able to provide support during the meeting and beyond where necessary. The focus group was conducted by Andrew Clifton who is a mental health practitioner, experienced in conducting research and evaluation with service users. Whilst focus groups were being conducted, the service user representative was available on-site to offer support for any participants who became distressed and wished to leave the focus group. Information was available for participants about other service provision to help with signposting where necessary (e.g. welfare agency, mental health charities).

Questionnaire data was both quantitative and qualitative. Descriptive statistics of the nominal data has been provided, for example presenting frequencies of key variables which had a "yes/no" response. Free-text data was thematically analysed.

Focus group discussions were analysed using Thematic Analysis (Creswell, 2007), shared themes were identified across each verbatim focus group transcript, and from the free-text components of the questionnaire. "Immersing" oneself in the data (Creswell, 2007), supports the beginning of thematic analysis by, e.g. reading and re-reading verbatim transcripts. From the transcriptions of the focus groups, all units of data (e.g. sentences and paragraphs) referring to a particular word or concept were given a particular code, these codes were examined in more detail and categories or "themes" (collectives of codes) identified. Preliminary analysis of the data was shared with participants and the process of "member checking" was undertaken to ensure trustworthiness and credibility of the data (Creswell, 2007; Robson, 2011).

Ethical approval was granted by the Faculty of Health and Life Sciences Research Ethics Review Panel, University of Northumbria, the employer of the researchers, which was sought and duly approved on 09/11/2012, project identification code: RE08-11-11297. A detailed process of informed consent was undertaken when recruiting participants. Full, detailed information about the consultation was given to SU both verbally at an information session conducted during one of the scheduled forum meetings, and in written format, describing both phases of the consultation. Potential participants were clear from this information that they were not obliged to take part and there would be no

adverse outcomes or impacts on their service provision if they chose not to take part. It was made clear that they could choose to take part in one or both of the phases (just questionnaire, just focus group or both). Returning the questionnaire was taken as participants' consent to take part in the questionnaire phase of the consultation, as is typical practice with questionnaire methods. At the beginning of the focus group, the researcher summarised the key aspects of the information regarding confidentiality and anonymity, data storage and the sharing of the findings. Written consent was then taken from each participant before the focus group began.

### **SUMMARY OF FINDINGS**

1. The current welfare system is unfit for purpose
2. It is dehumanising / degrading for people to go through
3. The process has a negative impact on health and wellbeing
4. There is a negative impact on financial resources for service users

### **RECOMMENDATIONS**

After presenting these results to participants of the consultation, as a collaborative group we offer the following recommendations:

- 1) Mental health service users do not have confidence in the current system particularly the "Healthcare Assessments" which are conducted by Atos Healthcare; a root and branch reform of the system is required.
- 2) Staff conducting the "Healthcare Assessments" should be non-judgemental, and sympathetic to the needs of mental health service users.
- 3) Forms and questionnaires should be written in "plain English".
- 4) Guidance on how to complete the forms should be provided and written in Plain English
- 5) Expert advice and support should be more widely available to assist mental health service users throughout the process.
- 6) Mental health service users should be offered more support and encouragement to re-enter the employment market.
- 7) The system needs to empower service users rather than criminalise them, which many mental health service users feel is the case.
- 8) The assessment process needs to take into account the individual context of service users rather than the current "target-driven" approach.
- 9) The requirement to constantly tell and re-tell the same problem-oriented stories time and again imposes additional strain on well-being.

- 10) Remove the cyclical nature of constant assessment which is de-grading and dehumanising.
- 11) Consideration must be given to the negative physical and psychological impact these reforms are having on mental health service users.
- 12) The weight of the financial implications for SU making ESA applications has negative impacts on their health and wellbeing

## RESULTS (1)

### *Results of Questionnaire*

15 participants completed the questionnaire and attend the focus day event facilitated by Andrew Clifton and Jane Noble. The questionnaire was developed in collaboration with researchers and service users to determine each participant's prior knowledge of the recent changes to the welfare system and the results are presented in Table 1 (below). The main issue to emerge from the questionnaire is that many participants in this consultation did not have enough information regarding the nature of the welfare reforms and how it may impact on them individually. This lack of information or to be more precise "inaccessible information" was one of the main issues to emerge throughout the consultation leaving many service users with a sense of frustration and disempowerment.

**Table 1**

Questions	YES	NO	NOT SURE	NO ANSWER/ NOT APPLICABLE
Did you receive a letter explaining the change, and what you would need to do?	8	5	2	
Did you understand the ESA50 Assessment?	5	7	2	1
Were you aware that in some cases dependent on savings that it might be stopped after a year?	6	6	0	3
At your Work Capability Assessment did the assessor treat you with dignity and respect?	6	4	0	5
Did you know that you could claim JSA or ESA but on a lower amount while waiting for a decision?	4	10	0	1
If you went to tribunal, did you feel you were treated with respect, fairly and that you were listened to?	6	3	0	6
Was your claim successful?	7	0	0	8
Were you aware that you will need to go through this process again in 6-12 months?	6	4	0	5

**Total: 15**

## RESULTS (2)

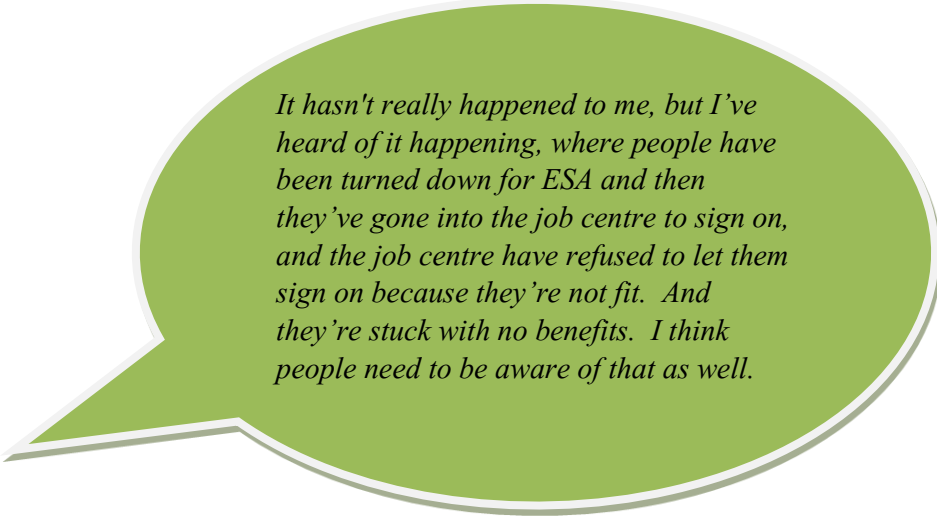
### *Results of Focus Groups*

In their focus group, participants discussed their experiences and perspectives of the recent welfare reforms. They describe a system that is unfit for purpose, degrading and dehumanising and which results in a significantly negative impact on their health and wellbeing.

#### **1. The system is unfit for purpose**

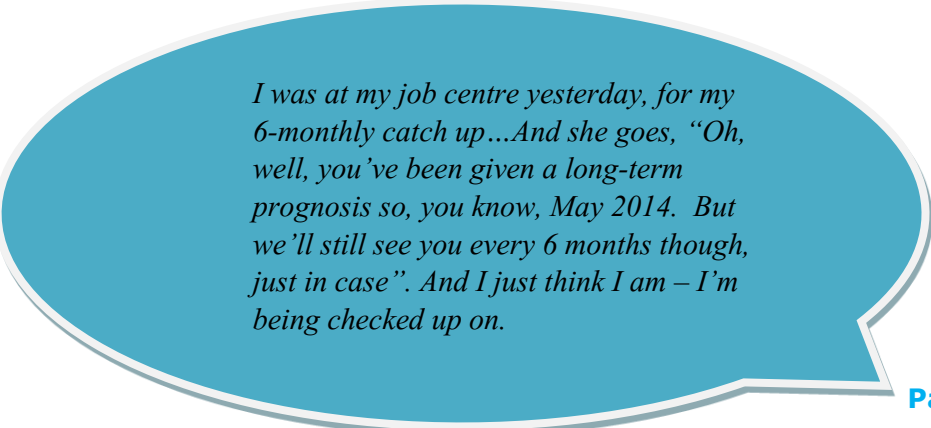
- *Constituent components of the system function independently*

Participants talked about their experience of the three different component parts of the system; ESA application form, WCA and tribunals. These three aspects function independently, working in isolation to each other. This lack of joined up working within the three component aspects of the system presents particular challenges to the service users who are required to access the system;



*It hasn't really happened to me, but I've heard of it happening, where people have been turned down for ESA and then they've gone into the job centre to sign on, and the job centre have refused to let them sign on because they're not fit. And they're stuck with no benefits. I think people need to be aware of that as well.*

**Participant**



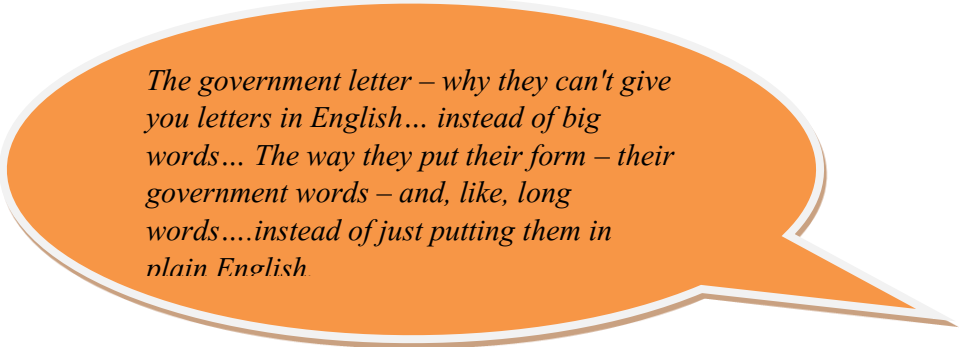
*I was at my job centre yesterday, for my 6-monthly catch up...And she goes, "Oh, well, you've been given a long-term prognosis so, you know, May 2014. But we'll still see you every 6 months though, just in case". And I just think I am – I'm being checked up on.*

**Participant**



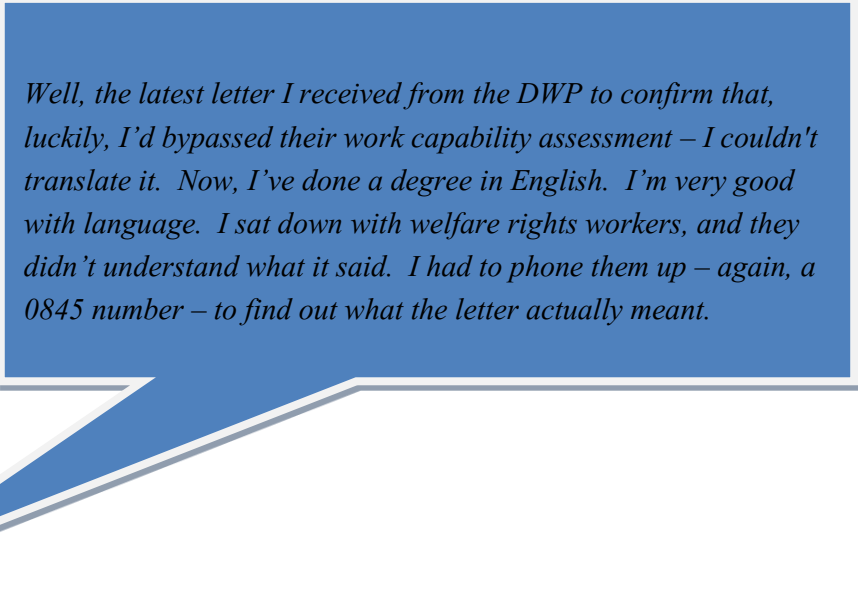
- *Inaccessible Communication*

Participants discussed that the communication and information within the system, for example the letters they receive and the forms to complete, are not written in an accessible format. The language used does not support clarity and comprehension; it is not "Plain English". Understanding the documents, and what is being asked of the applicant within the system, is therefore extremely challenging. This difficulty in comprehending the communication within the system is not associated with level of academic attainment or professional qualifications for participants. There are a range of qualifications and academic abilities across the participants in this consultation, including University Degrees and professional qualifications. The inaccessibility of the communication in the system was a key issue for all participants;



*The government letter – why they can't give you letters in English... instead of big words... The way they put their form – their government words – and, like, long words....instead of just putting them in plain English.*

**Participant**



*Well, the latest letter I received from the DWP to confirm that, luckily, I'd bypassed their work capability assessment – I couldn't translate it. Now, I've done a degree in English. I'm very good with language. I sat down with welfare rights workers, and they didn't understand what it said. I had to phone them up – again, a 0845 number – to find out what the letter actually meant.*

**Participant**

- *Lengthy, complex application form*

Participants discussed the length and format of the application form:

*It takes hours for you to fill it out, even if you're competent in filling it out; even if you're an expert in filling it out, it can take you two to three hours to fill it out.*

**Participant**

- *No support to navigate the system*

The participants in the focus groups discussed the fact that there is very little support for Service Users to complete the ESA application forms. The application form is written in inaccessible language and does not come with an information leaflet on how to complete the different sections, and what detail of information is required for some of the questions. Participants explained that service users are often unaware they can access support from some third sector organisations or are unsure where to go for the support.

*I mean, the first thing you do is you get the form through. And there's no real guidance on how to complete it. It's all very ambiguous. "Tell us about your illness or disability" and then you've got a box. Well, you can go on forever. But you'll go, "Oh, I've got this, this and this as well." So it's different ends of the spectrum. If people don't know how to fill out the form or how to describe or how to put into words what's wrong, what they can't do, you know, it needs... It needs to be clearer and it needs to be accessible. It's not accessible... There's no little leaflet that comes with it that tells you how to do it, or some advice.*

**Participant**

*I wouldn't have got through the last four years without the help and support of my mother. And, again, of other charities which I now volunteer for, because you want to give something back to these people who are there, working, stupidly long hours to help other people. To help you fill out your ESA 50s. The people who don't have their mothers to do it for them...to guide you through the entire process. There are these charities there, but what about the people who don't access these charities. Who don't know there are people there? There are a lot of people doing this on their own as well, and that must be so very isolating.*

**Participant**

Participants discussed the lack of government funded support for people within the ESA system, and the ways in which recent funding cuts have impacted negatively on the available support from the third sector;

*There's no government-funded mechanism to help people in the system. This is the con that Cameron was on about with the Big Society, where basically they pulled the funding from organisations that could help people, and then threw it into the arena for charities to pick up. So the only place you can go is charities. Places like Disability North or North Tyneside Disability Forum. And there's the Citizen's Advice Bureau, but they're not set for this anymore. All their funding has been pulled. There is one or two other about. But basically it's all charity-led. And it's led by people who are doing it for nothing....and workers...working ridiculous hours to help people because this government has abandoned them.*

**Participant**

As a result of the volume and complexity of the questions, the inaccessibility of the language used in the ESA application forms, and the lack of clear guidance information and support to navigate the three independently functioning aspects of the system, the service users feel the system is designed to stop people applying;

*With mental health problems, quite often you'll put things off, because you can't deal with them. And so it'll sit on the side, and then it's going to build and it's going to build and then it's going to build. And then it's too late, and then you're going to get sanctioned for not having it back in time.*

**Participant**

*...it's a well-known fact that people don't like writing in the first place. That's why, when you've got a complaint against a company, the first thing they'll do is say, "Well write the complaint in." 99% of people won't bother. The forms are made difficult on purpose, so you don't apply...plain and simple as that.*

**Participant**

- *Target-centred, not person-centred*

Participants explained that an independent insurance company has been commissioned to conduct the ESA assessments with applicants, and that the staff completing the assessments with applicants, are on financial incentives. Because of the target driven nature of the system, participants experienced a strong sense of being rushed through the system and reflected that individuals are not looked at in their own context; their own individual case, but instead people are "shoehorned" in to categories that are an incorrect "fit", as are the subsequent benefits;

*People are being rushed through the system without individual cases being considered. And people are being shoehorned into benefits that are wrong for them...it's a case of ticking boxes. The people don't care what you say, or how you look, how you act, how you feel. It's just a case of ticking those boxes on the computer. And, as I say, it's all financially-driven, because the more people they get of benefits, the more they get paid. The more people they get through the door, the more they get paid. So they're rushing people through without listening to them. And all they're interested in is making sure that they'll qualify to be taken off benefits.*

**Participant**

*My main concern, and I don't know too much about it, but the people that the government have been taking advice from in order to advise \_\_\_ on how to conduct these assessments are people who are used to do health insurance in America...this company – it's just basically their function has been switched. It's to deny people what they're entitled to. What they need. And it's okay; they're a health insurance company. They've got every right to prove if you... If you may be falsely claiming... But we're not falsely claiming. We're ill. We're unwell. And we have to prove this to people using questions that catch you out, that are wrong, that are inappropriate.*

**Participant**

*...It can't be right that the people who are assessing you are going to make financial gain out of you because that money could be used within the system.*

**Participant**

Many participants experienced judgemental, patronising or unsympathetic attitudes from these staff toward them when conducting the WCA assessments. Other participants experienced staff who were pleasant and professional, but who were constrained by the rigid format of the assessment interview.

- *Incorrect assessment and categorisation*

Participants discussed that 75 -80% of people who appeal their assessment win their tribunal and have their benefits reinstated, therefore illustrating that they had been wrongly assessed and categorised. Participants highlighted a conflict between assessment of fitness to work by the system and by employers, whereby some people who are told they are 'fit for work' often have a dilemma as some employers say they are not;

*What also happens – I take a lot of people to medicals and to tribunals... ESA tribunals and DLA tribunals... And the amount of tribunals that we win as a group is huge. I think it's in the region of 75 to 80%*

**Participant**

- *Not supporting people to move into employment*

Participants reflected that the system does not enable or empower people or support them to be able to exit the system and return to work;

*I'd like to add that I think there's middle ground as well. In that there are those who've been in... Let's say have used the services for quite a number of years, but who perhaps could get work with the correct support – and this particular system that's operating at the moment is not the appropriate support.*

**Participant**

In particular, participants discussed the current Government policies and the role these are playing in this lack of support for service users to exit the system, as the following exert from the focus group illustrates;

*Unfortunately the government has chopped Remploy now. With... So, with support and adequate provision there are people who can contribute to society. I, personally, value everyone in their social role. Unfortunately, government policies don't seem to do this.*

**Participant**

*Which is actually quite ironic since Mr. Cameron brought through the Big Society, isn't it, really.*

**Participant**

*Yeah, we're all in the same boat, apparently.*

**Participant**

*And George Osborne said we were all in it together.*

**Participant**

Later in the discussion another participant reflected on the damage that the closure of Remploy may have in the Region;

*And I would like to know as well the impact on the North East that closing Remploy has. Because I think that it's a disgrace. It really is.*

**Participant**

## **2. Dehumanising and degrading assessment system**

When participants described their own experiences and those of other service users known to them, they described a system which is dehumanising and degrading for people to go through, where people feel criminalised, judged, not viewed or engaged with as an individual, and powerless to interact with or respond to the assessment outcome.

*I've just had to fill a form...they do make you feel humiliated, degraded and like you're not bright enough, really, to be on this planet. That's how I feel. And they just make you feel as if you just... You're down there and we're up here, sort of thing. And it's not right, so I'm dreading it....when I get the letter.*

### Participant

- *Criminalising people*

Service users making an application for ESA feel under constant scrutiny; that they are being checked up on frequently due to the cyclical nature of the components in the system; assessments, appeals, tribunals, reassessments. Participants reflected that as a result of the continued surveillance they feel like criminals, and stated they are made to feel like "scroungers". Adding to the criminalisation of applicants is the interview style within the assessment for ESA, which participants liken to a police interview;

### Participant

*And it feels like you've been convicted of a crime that you didn't do*

### Participant

*[It's] like a check-up. You know, asking questions. I felt like I was being interviewed... It was like a police interview. And it's not to do with the lovely woman; it's to do with the boxes that she's got to tick on that computer.*

### Participant

*My tribunal was 45 minutes long, where I was intensely grilled by my doctor. And I understand that, really, they're looking for you to say the key phrase that they're looking for, in order to give you the award. But you shouldn't be interrogated for 45 minutes to try and get your case across.*



Participants reflected on the frequent alterations made to phrases and/or questions in the ESA form and assessment interview, which are designed so that more people can be deemed fit to work. Participants gave an example of the question where applicants are asked if they can pick an object up from the floor. Participants felt these alterations to questions were designed to “catch people out”;

*They change the... the testing criteria. For example, one of them, they'd sneak in the question for the tribunal, “Well, can you...? Would you be able to pick a coin up?” Now, it's not a coin. It's would you be able to pick a piece of cloth up? Because the criterion for that question is most people who had disabilities*

### **Participant**

- *Disempowering*

Participants spoke about their experiences of the power dynamics between themselves as applicants within the system, the medical practitioners providing statements, and the independent insurance company advisors who are assessing them and who have the final say in terms of their eligibility for benefits;

*The whole system relies on your specialists, etc., to back you up. And there's no way that specialists have got time and, in lots of places, the inclination to help you.*

**Participant**

Service users felt their lack of power in a range of ways, including having no power to challenge inaccurate summaries, statements or interpretations by the advisors who assessed their eligibility;

*I attended a recent appointment with my specialist, and I explained that my wife was parking the car and that... Anyway, to cut a long story short, I got a letter which said, "And George attended alone." And really, at that time, I felt that that was an inaccurate report. And I felt like challenging it. However, I felt it was futile. Because I don't think you can get past specialists sometimes, because they have the power. And as the mere patient, we, unfortunately, do not.*


## Participant

### 3. The negative impact on health and wellbeing

Participants described living in a constant state of increased anxiety, dread and distress which they experience in the "revolving door" or "vicious cycle" of forms, appeals, tribunals and reassessments that they are subject to within the system. Unsurprisingly, this constant and increased state of anxiety has a significantly negative impact on their health and wellbeing. Their continual involvement in a system which requires them to prove their incapacity to work, and therefore to detail their inabilities and illnesses, is in direct conflict with a positive focus on abilities and future steps, which supports their recovery, and their sense of competency in their ability to return to work. The financial implication for applicants within the system also has significant negative impacts on their health and wellbeing.

- *Increase in anxiety, fear and distress*

Participants all cited an increase in or constant state of anxiety, fear and distress, as they dread the assessments and each of the following stages within the system. This increased anxiety and distress directly compounds their abilities to live positively with their mental health difficulties, to move towards their recovery and to seek employment;



*I have to be perfectly honest, I know I'm going to be reassessed in the summer, and I'm starting to worry about it already. It's on my mind all the time. I take lots of people to tribunals, and a lot of people tell me they wouldn't go to the tribunals unless I was there to help them. And I've sat with people who've cried from beginning to end. I've sat with grown men and had to hold their hand through the whole process. I've had people who've been in absolute pieces because of the whole process, and then because of the verdict at the end of it. Basically, because these people didn't fit into little boxes... Or be able to answer the question to fit them into little boxes. Most of the people... I mean, everybody you take, they're either physically ill or mentally ill. The people who are mentally ill – and I think we're all mentally ill to one extent or another, to be honest with you – end up in pieces.... absolute pieces. Every one of them will tell you they feel guilty. They feel... that they're criminals. They feel that they're not believed. And it ends up that even the most innocent question can look like a trick question or something put there to trip you up when you're in that frame of mind.*

### **Participant**

- *A vicious cycle*

Participants reflected on the fear, anxiety and dread about the annual arrival of the ESA forms which signify the beginning of what they describe as a “vicious cycle” of completion of forms, assessments, medical reports, appeals and tribunals. Participants spoke of “dreading the brown envelope” landing on their doorstep.

Participants discussed the cyclical nature of the system; whereby if you are appealing your assessment (i.e. you have been assessed as fit to work therefore benefits withdrawn) the tribunal often takes 6 months to come, meanwhile benefits have stopped. If the tribunal outcome is that the applicant has been wrongly assessed, benefits are reinstated, backdated but no interest paid. It is then typically time for the next annual medical assessment in another 6 months. So it feels like the frequency of

assessment has increased; that the applicant is under constant scrutiny or assessment. This creates the sense of a cycle, and perpetuates the anxiety and sense of dread that service users feel in advance of the next assessment; perpetuating this state;

*So I went to appeal. And I won my appeal. Which overturned the decision – so the decision was wrong. And all the evidence that was there – that they'd given – was wrong. And... They say, "Oh, okay, we'll give you a year." And 6 months later I was being assessed again. And it's just relentless. They don't give you any time to recover, if you've got an illness. And it just sends you back to the beginning...to the whole process again. It's an endless circle. It really is.*

**Participant**

*The other thing about that is – is that there are 6-month waits for your tribunal to be heard. So you might win your appeal and you'll get called in for another medical 6 months later... It just makes the frequency even worse*

**Participant**

Participants talked about being trapped within this cyclical system, with the most vulnerable to this being those with long term mental ill health;

*The people who are caught in the mincer of... Of this system, are the people who are long-term sick? The short-term sick aren't caught within it, because they get over their illness, they get a job and they go back to work. The people who are caught in the grinders of this system are the long-term ill, who can't get a job and can't get out of the system.*

**Participant**

The cyclical nature of the system means that the applicant undergoes constant questioning, both within the system and self-directed questioning e.g. "am I better"? The ESA forms are annual but the tribunal to appeal the decision of ESA can take 6 months, so it feels like every 6 months there is a reminder for people; "how far have I come?" "Am I better yet" and this has a detrimental effect on their sense of being able to move forward;

*You've got the anxiety of are you going to get that brown letter through the door. And... Oh, well should I be feeling better now? You know, it's... It feels like you've got to put a time frame on things when, for me personally, it's mental health issues. And, you know, you don't know when you're going to get better. You can't... You just try and take every day as it comes. But then you're getting a letter through the door and you're thinking, "Well, how far have I come in 6 months?" And, you know, it makes you question everything you thought you knew about yourself.*

**Participant**

*Well, I got my ESA 50 through last September. 6 months after my tribunal. And I spent 24 hours crying. Because I thought, "Oh, well how was I meant...? Was I meant to be better by now?" I hadn't come as far as I wanted to be. It makes you ill. It makes you worse. It makes you ask questions about yourself that... That you wouldn't ask. It's not right. It makes you doubt yourself. It makes you think, "Am I lying? No. What's wrong? Am I ever going to get better? Am I going to have to go through vicious circle again? Is this the beginning of another 6 months of assessments and tribunals and meetings and forming statements and...?" You despair.*

**Participant**

- *Battle weary*

Participants in the focus group reflected that claimants already feel 'worthless and judged' and having to fight for the entitlement to 'benefit' has a major negative effect on their mental health. Participants described the constant fighting for the right to receive ESA as a daily, never ending battle which has left many service users feeling suicidal. The support providers then have to deal with the consequences;

*We're dealing with people here who have – some of whom – have got profound emotional mental health difficulties, issues and...There is no balance to it... So what are they doing to compensate? They are doling out these procedures. It's having this impact on people...I do claim invalidity. And maybe I'm feeling, oh, it's not going to hit me. But that's not the way I'm feeling at this moment now, because I'm thinking maybe it could shortly. And the type of difficulties I have, if my illness returns, I could die. Where is your compensation for that, then, and where is your balance? Where is the justice in this?*

**Participant**

- *Illness-focused*

The impact of the telling and re-telling of their "problem oriented" stories is particularly damaging for the service users' health and wellbeing. The system demands that applicants focus on what they can't do, as requested in the ESA forms and in the tribunals to appeal against decisions to withdraw benefits. This is in direct opposition to the positive perspectives and day by day approach that is promoted to support wellbeing and recovery for people with mental health difficulties;

*It makes you also focus on the negative things....because you've got to prove your illness. Prove your illness again and again and again. When, really, what you want to be spending that energy on is healing yourself and, you know, looking to see what you were...what sort of things you can manage to do. Whether that is volunteering or paid work or... You know, developing your confidence or whatever. And it's... It's actually really counter-productive.*

**Participant**

*Like, because I think the whole system can and does make you feel worse. It highlights what you can't do. It's a 6-monthly reminder that you're still unwell.*

**Participant**

*And I've been for a...a tribunal. Which I passed....but it was a very harrowing experience. And I wouldn't like to go through it again, really. So I feel sorry for people that have to go through all that as well. I don't think we should... Sorry, I don't think we should have to go through all that, because I think once you've passed the assessment, it makes you more anxious and more depressed and you can't really go out and get a job if you're feeling like that, you know. It makes you worse. So that's my feeling on it.*

**Participant**

#### **4. The negative impact on financial resources**

Participants discussed the negative impact of the system on their finances and their ability to live day to day. Participants reflected on their own, and other service users', experiences of being unable to afford to live when benefits are withdrawn;

*You know, there's people who can't afford to eat. They can't afford to have a pet anymore. Yes, okay, that might be a luxury. Oh, that's a question asked in your work capability, actually, isn't it? Yes – do you have a pet? And that can be used against you.*

**Participant**

### *The financial cost of the vicious cycle*

Typically service users accrue debts during the 6 month period whilst they wait for their tribunal to appeal the decision to remove benefits. If they are successful at their tribunal, their benefit is paid in arrears, with no interest. This backdated benefit sum is used to pay back their accrued debts, and then the 'benefit' cycle begins again. Participants explained that poverty is increasing and many people are becoming more isolated, unable to travel anywhere and pay the bills, and cannot afford to eat healthy food;

*[When I was initially declined on my second assessment my money stopped]...I had to get everything reinstated. But then I was back at the assessment rate until my tribunal, which was 6 months away. So I'm then on the lower rate – even though I was previously being awarded the higher rate...And it was only once...my decision was overturned at tribunal. I got the arrears paid back – which is a hefty sum... And you suddenly realise this... That money – I didn't see any of it, because I had to pay back the debts that I'd accrued over that time.*

### **Participant**

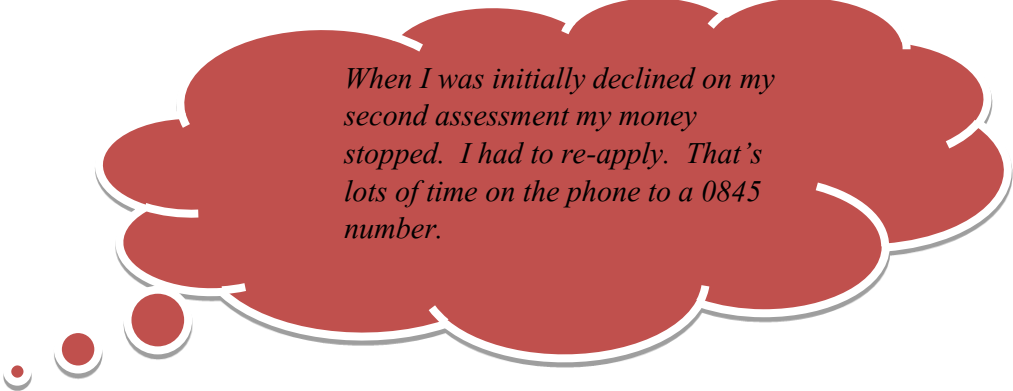
*While people are in that situation, they can lose their house, they can lose their marriage. They can lose everything. [They] get everything paid up, but by the time they get it paid up – as I say, without interest – it's too late...because they're on the street. It's a long period of time to be without any money....or on less money than you're used to getting.*

### **Participant**



- **System costs for claimants**

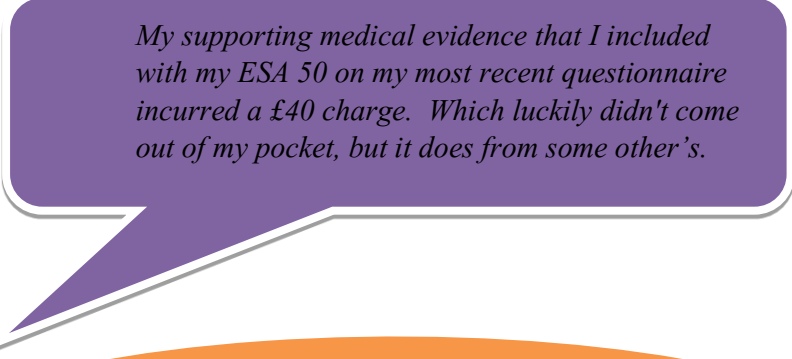
Participants discussed the financial expense of calling the 0845 telephone numbers to appeal the ESA assessment or to ask questions about any aspect of the system;



*When I was initially declined on my second assessment my money stopped. I had to re-apply. That's lots of time on the phone to a 0845 number.*

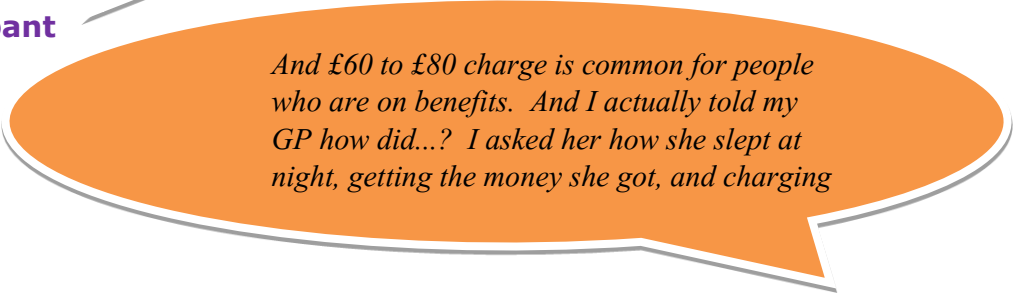
**Participant**

They also cited the financial cost of the medical report or supporting medical evidence that is required to accompany their application; typically £60 to £80, which applicants often have to pay themselves;



*My supporting medical evidence that I included with my ESA 50 on my most recent questionnaire incurred a £40 charge. Which luckily didn't come out of my pocket, but it does from some other's.*

**Participant**



*And £60 to £80 charge is common for people who are on benefits. And I actually told my GP how did...? I asked her how she slept at night, getting the money she got, and charging*

**Participant**

- *Impact of additional reforms*

Participants discussed the additional reforms to the welfare system, for example, the Bedroom Tax, which create an additional financial expense and which, interacting with their experiences in the ESA system, create a significant negative impact on their financial situation;

*I just want to mention a friend of mine's situation, really. He's about to go for a medical, but like every other time he knows he's going to be turned down. Unfortunately, recently, the council are also changing the benefit for people in council flats, and he's got an extra bedroom. He's worked out that he's going to have £3 a week to feed himself on, if he's put down to assessment and the bedroom tax is taking another £15 a week off him. He's already down to the bare bones. He's got no internet; he's got no landline phone. And he's got absolutely nothing. And it's a really worry. I'm worried about that, as much as I am about myself.*

**Participant**

*And another thing I don't like now is going to hospital – because I think I've got to have another stomach operation soon. They've got a new cut-off date now, apparently, where you're only allowed 14 days, whatever. After that 14 days, if you are still bad, they stop your housing benefit and you've got to start all again. So you've got to either get out before the 14 days, or God knows. And that's it.*

**Participant**

*I'll tell you what I'm angry about – I had a psychiatrist, and I was really unwell about a year and a half ago. Unfortunately, the psychiatrist and I didn't see eye to eye, because he was very inappropriate towards me. I had been trying to get a psychiatrist for the last year and a half, but North Tyneside are saying that it's the funding. If they haven't got the funding, I can't get another psychiatrist, so I'm in the process of still waiting to get help. In other words, well, it just depends... You just have to wait and see if, for some reason, Newcastle can afford to take you on. So I'm just stuck in the middle, trying to get help, really...which I should have had 18 months ago. Which means I can't have a CPN and I can't get CBT or psychological therapies... so... that's where I am at the minute. And I really detest... Detest the way things are going. But there's just nothing I can do, unfortunately.*

### Participant

Participants suggested that the impact of the interrelation of funding cuts within the recent welfare reform is likely to result in increased psychiatric hospital admissions, and an increase in crime rates;

*No, I was just thinking that a lot of the cuts already on – around the benefits and everything else – I think it's going to see a bigger rise on the population of prisons...and some hospitals. You know, people getting... using, like, psychiatric disorders, or psychopathic disorders. Like that one... Just to get into hospital or prison. It's going to cause a lot of that. With the ...welfare reform...it's going to cause a lot of people going into, you know, burglaries...more crime.*

### Participant

*I mean, it's a totally different subject altogether, but mental health and crime rates... I think if they really looked into the causes of crime and all the rest of it – and mental health of people in prisons...Because people are just being locked up in prison for... because they can't cope with society. And if society is going to keep failing you, then you're going to fail society as well. But it's like opening a can of worms.*

**Participant**

Participants reflected that they would like to share the findings of the report with the government to raise awareness of the lived experience of the current welfare reform;

*The government can listen to the outcome of this report – which is based on the real findings of real problems of real people. And all of these government, politically-led... things, are having huge...a serious impact. And we're hearing people's stories today. That's what they can do – they can listen and hear what the report is saying.*

**Participants**

## **DISCUSSION**

The quotation above from one of the participants of this project perfectly summarises the rationale for conducting this consultation - to provide a platform for mental health service users to tell their individual stories of their experiences of recent welfare reforms. The aim of the consultation was to ensure that these stories are shared by the Service User Representative in her remit within the NHS Trust, so that future healthcare service development can be informed by a wider understanding of service user experience.

Participants have reported on the inaccessibility of the communication within the current ESA application system; there is a lack of information and guidance, and all letters and application forms are not written in Plain English.

Participants reflected that the system is unfit for purpose. Navigating through the three independently functioning aspects of the system significantly impacts negatively on SU health and wellbeing. Participants report significant increases in anxiety, fear and dread at anticipating the beginning of, and during, each cycle or "round" of ESA applications. The process of application and assessment is described as dehumanising, degrading and criminalising. SU talk about the demonization they experience and the accumulative impact of having to reflect on, present and give evidence for everything they are unable to do, in order to qualify for ESA. This is in direct conflict with the solution focused approach of their treatment and recovery programmes, and potentially damages any positive outcomes from their treatment.

Rather than focusing on what positive steps they are making, both in terms of health and wellbeing, and ability to/readiness for re-entering employment, the system requires them to focus on all their difficulties, their incapacities and their inability to contribute to employment. The system privileges incapacity; not progression, improvement or achievement. Participants experience high levels of anxiety and distress at this evidence of not being "better". This does not support the development of resilience in SU, of which self-efficacy is a vital component. Building resilience is acknowledged to be necessary in order to strengthen mental health (see Davydov et al, 2010 for review). Therefore it could be argued that the system is contributing to their ill health and is impeding their progression.

The financial implications are severe for applicants within the system; including requirements to call premium rate telephone numbers and pay for medical reports / assessments. When benefits are suddenly removed or severely cut, and appeals and tribunals are required before the benefit can be reinstated, SU typically accrue significant debt and can lose their homes and families. The co-morbidity or correlation between mental health and financial difficulties and debts are well documented (See systematic review by Fitch et al, 2011).

Participants reflected on compounding variables resulting in additional challenges and barriers for them in navigating the system; including the Government funding cuts which mean less third sector support is available to them.

In summary, participants reflected on the disempowering effects of the ESA application system. SU do not question the necessity for assessment for eligibility for ESA, and

emphasise the importance in ensuring that benefits are required and that people are not cheating the system. However it is the way the system runs; the aims and goals of the system being focused on proving incapacity rather than exploring progression and increases in abilities, which locks SU in disempowerment and disability. The lack of joined-up working between the three component aspects of the system, and competing mind-sets between the system and the health and social care services that are engaging with the same SU to support their health and wellbeing, create an impasse for SU between recovery and incapacity.

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