



Reassessing assessments

How people with mental health problems can help fix the broken benefits system.

March 2023

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Executive Summary

Getting the right benefits can help those of us with a mental health problem to live with independence and dignity. This requires fair and accurate benefits assessments. But right now, that's not what we have.

In this research, those we spoke to told us the benefits assessment process can feel like 'being put on trial'. People feel mistrusted and judged. As if they were just trying to get out of working, despite wishing they were well enough to work. Many said that their mental health got worse as a result.

The stories we heard made it clear that people with mental health problems are not treated with dignity and respect. This needs to change.

Our support systems should work for and include everyone in our society. Through this research, people with mental health problems told us how the UK government can change benefits assessments to effectively support them.

People with experience of the benefits system must be at the heart of how to improve it.

The UK government should:

- 1. create a new commission – one that is led by disabled people** tasked with proposing reforms to the structure and criteria of benefits assessments.
- 2. establish an independent regulator for the benefits system** to hold the UK government to account, protect the rights of disabled people, and enforce improved assessments.

What we did

This report summarises the experiences and views of people in England and Wales with mental health problems and experience of benefits assessments. The findings were gathered via a poll of more than 1000 people and workshops with 24 people who had experience of being assessed for Personal Independence Payment (PIP), Employment and Support Allowance (ESA) or Universal Credit (UC).

Our aim was to see how assessments can be improved to work for everyone. And to develop solutions grounded in people's lived experience.

Our key findings

1. There's still a **lack of understanding of mental health problems** throughout the benefits assessments system.

2. People felt that **the system tries to catch them out**, rather than support them.
3. **People felt confused, angry and retraumatised** when trying to navigate their assessment.

This was supported by our polling findings:

- Almost 1 in 2 people (48%) did not agree with the outcome of their PIP assessment.¹
- More than 1 in 3 (35%) did not agree with the outcome of their assessment for ESA or UC.¹
- Almost 7 in 10 people (66%) told us that going through their benefits assessment made their mental health worse.²
- Both female and older respondents were most likely to have negative experiences of assessments.
 - Almost 9 in 10 (88%) of female respondents aged 45 and over told us that their PIP assessment made their mental health worse.²

Recommendations for improvement

Workshop participants told us how they felt benefits assessments could be improved.

Fundamental to these recommendations was the need for the UK government to change its overall culture within the benefits system. A shift is needed from gatekeeping benefits to prioritising support for disabled people. The UK government must trust, listen to and work with disabled people to take forward their recommendations for assessment reform.

It should take the following approach:

1. **People should be able to choose their assessment method and time.** Some people may struggle to attend a face-to-face assessment, whilst others may not be able to explain their situation properly over the phone.
2. **The process should be easier to navigate.** This includes providing more information about what the process involves. And offering flexibility in the process so it can work for everyone.
3. **Assessment questions and criteria need to reflect the reality of mental health problems.** Better questions need to be asked, including ones which account for fluctuations in people's mental health over time and which assess how work can affect people's mental health.

4. **Fewer assessments should be carried out.** More benefit awards should be made based on the forms people fill in and the evidence people provide from health professionals. The length between reassessments should also be extended to reduce the stress of repeatedly going through the same process.
5. **Assessors need more mental health expertise and to be more understanding.** Assessors should be required to have a mental health qualification or training when dealing with benefit claims that are based on mental health problems. Overall, their approach needs to be more sympathetic to the additional barriers people are facing.
6. **The accountability of assessors and decision makers needs strengthening.** Assessments should be automatically recorded and provided to the person making the application. Assessors' performance, in terms of quality and accuracy of assessment reports, should also be monitored more and held to higher standards.

Introduction

The current benefits system is not working to give those of us with mental health problems the financial support we need. Unfair and inaccurate health assessments are leaving many people having to go through lengthy, stressful processes to fight for benefits to which they are eligible, while they are unwell. The health assessments used by the Department for Work and Pensions (DWP) to determine eligibility for Personal Independence Payment (PIP), Employment and Support Allowance (ESA), and Universal Credit (UC) are in desperate need of reform.

As the cost of living crisis continues, it's even more important that people get access to the financial support they need. It is well known that there are many issues with these assessments, which ultimately cause harm to many people with mental health problems. Approximately 1 in 3 people applying for and receiving PIP³ and 1 in 2 people receiving ESA⁴ have a mental health problem, cognitive impairment or learning disability as their main disability.

In 2021-22, over 550,000 people in England and Wales applied for PIP. 52% of people had PIP awarded to them, and 48% did not.⁵ Of those who ultimately went to a tribunal hearing to appeal their PIP decision that year, 7 in 10 people won their appeal.⁶ This is a strikingly high success rate. In 2022, up to March, 59% of PIP decisions which were overturned at tribunal were due to the tribunal reaching a different conclusion on substantially the same facts. 32% of successful appeals were overturned because the courts heard more convincing oral evidence.⁷ This suggests that often the right questions are not being asked, and when they are, things are going very wrong in the decision-making process. Specific statistics on appeals of outcomes of health assessments for UC are not currently published. However, we know that for ESA, which uses the same Work Capability Assessment (WCA), in 2021/22, 6 in 10 appeals which reached a tribunal hearing were successful.⁸ **It is clear that, by any measure, the current PIP assessment and WCA are not working.**

In October 2020, we published our report, *People, Not Tick-boxes*⁹, with recommendations on how to change the culture of the benefits system for disabled people. In this report, we continue the argument that the best way for the UK government to improve benefits assessments is to establish a commission led by disabled people to reform assessments and create an independent regulator of the benefits system.

In summer 2021, the DWP looked at reforms to assessments in its *Health and Disability Green Paper*.¹⁰ Despite acknowledging issues with assessments, it did not make enough tangible proposals for reform or say how it would address the fundamental problems with the benefits system.

With this in mind, we held workshops with people with experience of mental health problems and a health assessment for PIP, ESA and/or UC. We wanted to put forward their ideas, and to illustrate to the DWP that disabled people should be trusted to redesign assessments. We also carried out polling, to capture the experiences of benefits assessments across a larger number of people with mental health problems.

We believe the answers to improving benefits assessments are grounded in people's lived experience. Our recommendations represent the views of the people with mental health problems who shared their experiences and views of the benefits system. They show the types of practical reform that are needed, and that lived experience gives people expertise in how a system should work. We have made these recommendations to the DWP, who we hope will take the opportunity of the Health and Disability White Paper to make real improvements to assessments.

Current DWP guidance on PIP assessments and WCAs

The DWP guidance states that the PIP assessment is used to determine a person's ability to carry out a series of everyday activities.¹¹ The WCA is used to find out how much a person's health condition or disability affects their ability to work.¹²

Assessments are used to determine the level of financial support someone receives, plus, in the case of the WCA, whether they are required to undertake activity to look for or prepare for work. The WCA is used in ESA and UC.

WCAs are carried out by the Centre for Health and Disability Assessments, operated by Maximus. Atos and Capita carry out PIP assessments, each holding the contracts for different regions in England and Wales.

Benefit applicants' questionnaires are sent to these assessment providers, who are then responsible for assessing the applicants' health. This is based on the application forms, going through the evidence, and usually through a live assessment (either in person, on the phone or through a video call). The DWP then makes the decision about a person's eligibility based on an assessment report from the respective assessment provider.

Methodology

We undertook both quantitative and qualitative research, using polling to understand experiences of assessments across a larger group, and workshops to look in detail and people's experiences and ideas for reform.

Polling

In February 2023, we commissioned polling of people with mental health problems with experience of benefits assessments. The polling was conducted by Censuswide with a sample of 1,003 people in England and Wales who have had a health assessment for benefits, related to their mental health problem(s). The survey fieldwork took place between 1st and 6th February 2023.

The demographics of the people we polled were:

- 2 in 3 survey respondents were female and 1 in 3 were male.
- 5% of respondents were based in Wales, and 95% in England.
- 13% of respondents were aged 16-24, 32% were 25-34, 26% were 35-44, 18% were 45-54 and 11% were 45-54.
- The ethnic backgrounds of respondents were:
 - 6.5% of respondents were Asian or Asian British
 - 3.6% were Black or Black British
 - 85% were White or White British
 - 3.7% had a Mixed ethnicity background.
 - 0.7% had another ethnic background.

Men and people from Asian and Black ethnic backgrounds are under-represented in our poll compared to the general population. Unfortunately, our results are therefore skewed more towards the experiences of women and White people. We have not been able to make comparisons between experiences of people from different ethnic backgrounds as we did not poll enough people from each ethnic group for this to be statistically meaningful. We will undertake another project to explore the experiences of people from minoritised ethnic backgrounds of benefits assessments.

Of the people surveyed, 592 people told us about their experience of their latest PIP assessment and 662 people told us about their experience of their latest assessment for ESA or UC (this is the WCA). The majority of people had experiences of assessments in the last two years. Of those who had a PIP assessment, 46% had their latest assessment in the last year, 31% 1-2 years ago, 17% 3-5 years ago and 5% had their last assessment 6 or more years ago. Of those who had an assessment for ESA or UC, 42% had their latest assessment in the last year, 28% 1-2 years ago, 17% 3-5 years ago and 9% 6 or more years ago.

Workshops

In May and June 2022, we carried out three workshops with 24 adults with mental health problems with experience of health assessments for benefits: the WCA and PIP assessment. All participants had an assessment within the last five years, and many of the experiences they discussed were more recent than this.

The aim of these workshops was to hear people's ideas of how benefits assessments can be improved and what good benefits assessments could look like. For these workshops, we wanted to focus in on solutions: we explored how to resolve the issues people had faced, and how assessments can be made to work for people with mental health problems. Key themes were identified using a thematic analysis of the notes.

People's experiences and ideas for improvements covered the same issues, whichever assessment we were discussing, and recommendations were applicable to both the PIP assessment and WCA.

The proposals are not intended to be exhaustive. They do not consider specific reforms needed for the system to work for other disabilities or health conditions, although many of the people in our workshops had other health conditions as well as their mental health problem. Pseudonyms were used throughout the report to protect participants' anonymity.

Thank you

We would like to thank our workshop participants for taking the time and energy to speak to us so openly about their experiences of benefits assessments and telling us what a better assessments system would look like.

We are grateful to Diverse Cymru and Taraki for sharing our call-out looking for people to take part in the workshops. Thank you also to Ayaz Manji for valuable comments on an early version of this report, and to Censuswide for helping us to quickly gain insights into the experiences of a wider group of people with mental health problems.

Thank you, Layla Hussain, for your support in designing the workshops, the workshop analysis and your input to the report. Thank you Charlotte Payne, Nil Guzelgun, Vicki Nash and Sophie Corlett for your feedback and support in refining the report.

How assessments should be improved

Polling findings

Far too many people with mental health problems are having negative experiences of benefits assessments. The majority of people say their assessment made their mental health worse and that the questions asked do not reflect the reality of their mental health problems. Large numbers report that they feel their assessor did not understand mental health problems. Almost 1 in 2 (48%) people who had a PIP assessment and over 1 in 3 people (35%) who had an assessment for ESA or UC did not agree with the outcome of their assessment.

These are huge issues for people to be facing. We have laid out findings that show it is not a small minority of people who have these criticisms of the system. They also show that more women, more people aged 45 and over, and even more people aged 55 and over, are having these poor experiences. The DWP and assessment providers must work to understand why this is happening and address these issues.

Assessments can make your mental health worse:

- Almost 7 in 10 (69%) respondents who've been assessed for PIP agreed that going through the benefits assessment made their mental health worse.²

Older people and female respondents were most likely to tell us their assessment made their mental health worse:

- 81% of people aged 45+ felt the assessment made their mental health worse, compared to 59% of 16–24-year-olds.
- 74% of female respondents agreed it made their mental health worse compared to 60% of male respondents.
- Looking at these identities together, we see that 88% of the 112 female respondents aged over 45 that we surveyed agreed that their PIP assessment made their mental health worse.

The assessments for ESA and UC are also causing considerable damage to people's mental health:

- Over 3 in 5 (62%) respondents assessed for ESA or UC agreed that going through the benefits assessment made their mental health worse.²

Again, this was felt most often by older people:

- 73% of people aged 45+ felt it made their mental health worse, in comparison to 43% of people aged 16-24.
- Similarly, women (65%) were more likely than men (56%) to report that it made their mental health worse.

The proportions of people who are reporting their mental health deteriorated due to going through assessments are substantial. Women aged 45 and over are finding the process particularly damaging and more must be done to look at why this is happening. It is unacceptable that a system which should be supporting people when they are unwell, is instead making them more ill.

Assessors lack understanding of mental health problems:

- 46% of respondents assessed for PIP, and 36% of people assessed for ESA or UC, felt their benefits assessor did not understand mental health problems.¹³

Again, we see a difference by age and gender:

- 59% of respondents aged 45 and over felt their PIP assessor did not understand mental health problems, compared to 34% of 16-24 year olds.
- Similarly, 51% of women felt this, while 35% of men did.

Thinking about their last ESA or UC assessor:

- 51% of respondents aged 55 or over and 31% of 16-24 year-olds felt their assessor did not understand mental health problems.
- On the other hand, 37% of women and 33% of men felt this. So, there was a smaller difference by gender for people who had an ESA or UC assessment.

These are high proportions of people feeling that their assessor does not understand mental health problems. In these cases, it's unclear how assessors can be properly assessing how someone's mental health affects them. There is work to be done to improve how assessors understand and treat people with mental health problems. Given the notable differences between gender and age groups, the DWP and assessment providers should look at whether people are being treated differently depending on their demographic characteristics.

Assessment questions aren't always reflecting the reality of mental health problems:

- 60% of people assessed for PIP and 52% of people assessed for ESA or UC agreed that the questions during their assessment did not reflect the reality of their mental health problems.²

As we've seen with previous questions, the difference between age groups was high among people assessed for PIP:

- 84% of people aged 55+ agreed with this statement as opposed to 54% of people aged 16-24.
- In line with previous trends, more women agreed with this statement (63%) than men (55%).

For ESA and UC, there was a smaller difference among age groups:

- 46% of people aged 16-34 agreed, and 58% of people 35 and older agreed.

And a minimal difference by gender:

- 54% of men and 52% of women agreed.

Assessment questions are not reflecting the reality of the majority of people's mental health problems. This suggests the criteria used to determine eligibility for benefits is also not adequately reflecting the way people experience mental health problems and it may be particularly out of sync with the way older people experience or talk about mental health problems.

Many people don't have trust in the DWP:

- Only 35% of respondents assessed for PIP agreed that they trust the DWP to help them get the financial support they need, whilst over 2 in 5 (44%) disagreed.²
- 40% of respondents assessed for ESA or UC agreed that they trust the DWP to help them get the financial support they need, while 38% disagreed.²

For both assessment types, male respondents were more likely to agree with this than female respondents:

- 41% compared to 32% for PIP.
- 45% compared to 38% for ESA or UC.

Older people were also less likely to agree:

- Just 23% of people aged 55 and over who have had a PIP assessment trust the DWP to help them get the financial support they need.

People with mental health problems should be able to trust that the UK government department responsible for administering benefits can and will support them to get the financial support they need.

Lots of people disagree with their assessment outcomes:

- Almost 1 in 2 (48%) people who had a PIP assessment did not agree with the outcome of their assessment.¹ Of these, nearly 3 in 5 (59%) appealed against the outcome.

PIP assessments should not be leaving half of the people who go through them disagreeing with the outcome. As with previous questions, older age groups and women were more likely to disagree with their outcome:

- 61% of over 55s did not agree with their PIP outcome, compared to 36% of 16–24-year-olds.
- 52% of female respondents did not agree compared to 40% of male respondents.

Of all respondents who disagreed with their PIP outcome, 71% felt that their assessor did not understand mental health problems¹⁴ and 73% said the questions asked during the assessment did not reflect the reality of their mental health problems. This highlights two key issues which are stopping people getting the support they need, which we explore in our workshop findings below.

Of the respondents who did not agree with their PIP outcome and did not appeal, 75% felt their assessment did not take into account their mental health problems.¹⁵ We are concerned that 41% of people who disagreed with the outcome of their PIP assessment did not appeal the decision, leaving large numbers of people without the financial support they need. This suggests that these people are so disheartened by a process that does not properly consider them, that they are left feeling unable to fight it.

- Over 1 in 3 (35%) people did not agree with the outcome of their assessment for ESA or UC.¹ Of these, 57% appealed the outcome, and 43% did not.

Fewer people disagreed with the outcome of their assessment for ESA or UC than for PIP. The proportions of people who went on to appeal the outcome is similar to PIP outcomes. Interestingly, views on the outcome of ESA and UC assessments did not vary considerably by age or gender, as they did with PIP. This is still a high number of people disagreeing with the outcome of their assessment and again highlights issues with the assessment process. We explore these issues in our workshop findings below.

Your gender and age impact your experience of benefits assessments:

Our polling findings have shown considerable differences in experience of benefits assessments by gender and by age. The biggest factor appears to be age, as more people from older age groups have reflected negative experiences than people from younger age groups, across assessment types. Respondents aged 45 and over were more likely to report a worsening of their mental health from benefits assessments and were less likely to trust in the DWP to be able to help them gain financial support. Those aged 55 and over were least likely to agree with the outcome of their assessment, that questions reflected the reality of their mental health problem, or that their assessor understood mental health problems.

More female respondents reported negative experiences than male respondents, though this difference was less pronounced for ESA and UC assessments than PIP assessments. Female respondents aged 45 and over most frequently had poor experiences of assessments. More must be done to understand why this is happening, and to understand the experiences of non-binary and trans people, too. The government and assessment providers need to look at how policies and practices may be making the process harder for women and people aged 45 and over, and especially aged 55 and over.

They should explore whether:

- Assessment questions reflect how younger people talk about their mental health, rather than older people.
- More needs to be done to put older generations at ease, as older people tend to be less comfortable speaking about their mental health.¹⁶
- Assessors are showing less understanding to older people and women.
- Assessors and decision makers hold biased beliefs that are clouding their judgement of older people and women.
- Non-binary and trans people might be subject to similar biases described above.

Workshop findings

In our workshops, participants spoke in detail about their experiences. While we did ask people about what went right for them, the vast majority were not able to speak to this, and instead they spoke of the many problems they faced. We sought to understand where the problems were for them, and the ideas they had for how a reformed benefits assessment could work. There were clear themes within what participants told us about the issues they faced with their benefits assessments, and the solutions they suggested. These form the basis for our recommendations:

1. People should be able to choose their assessment method and time.
2. The process should be easier to navigate.
3. Assessment questions and criteria need to reflect the reality of mental health problems.
4. Fewer assessments should be carried out.
5. Assessors need more mental health expertise and to be more understanding.
6. The accountability of assessors and decision makers needs strengthening.

Below, we detail what workshop participants told us about their experiences and how they felt the system needed to be changed. The solutions have come directly from the participants and reflect what they felt was important.

1. People should be able to choose their assessment method and time.

The problem: Participants told us that the assessment method and the way assessments are allocated are both causes of stress and anxiety. Too often, in the past, an in-person assessment would be given despite it not being suitable to an individual's needs. Since the pandemic, most assessments have been on the phone, with little choice. While people can now request to change their assessment method, many people are not aware of this, which adds another source of stress onto an already difficult situation.

When carried out in person, people can be required to travel to assessment centres that are far away, which can further exacerbate their anxiety during an already stressful process. Allocating an assessment centre that isn't easily accessible without being able to choose an alternative method also affects the support they receive on the day, as advocates, family or friends may not be able to make these journeys.

Currently, people are only able to change their assessment appointment time once. If they cannot make the rearranged time, people are at risk of having their benefit claim stopped or rejected, or having to restart the process. Participants highlighted that they found this unfair.

The solutions:

People should be given a choice about what assessment method they have (whether that is in person, on the phone or by video call). The impact of mental health problems varies between individuals, so the methods in which they are assessed should account for this. An in-person assessment might work for some, but phone or video assessments are more beneficial to others. This choice could be offered in the initial application forms to help reduce the amount of correspondence needed. Along with this, people should have full information about how each assessment method would work (for example, whether they need a certain app on their phone) and where their local assessment centre is.

People should be able to choose their assessment time from multiple options. To make sure an assessment time works for someone, as well as anyone they need to bring to support them, they should be able to choose the date and time from a list of options.

People should be able to reschedule their assessment more than once. People's schedules can change, or other factors such as a period of worse mental health problems may prevent them from being able to attend an assessment. The process needs to be more flexible to allow changes.

2. The process should be easier to navigate.

The problem: Participants found the assessment process too complicated. They felt that the initial forms and assessments were too long and involved a lot of repetition. One participant described the paper application as a massive pile of documents that was overwhelming and increased anxiousness. For someone with mental health problems, having to explain your condition multiple times can be at best exhausting and in the worst cases retrigger trauma and distress.

Currently, people have four weeks to return the forms in which they detail how their health affects them (the PIP2 form, ESA50 form and UC50 form). These are long forms, with up to 38 pages to fill in, and can be time-consuming to complete. Compiling evidence to go with the forms is also difficult.

The process is also hard to understand and hard to access. There is currently little support available to explain the assessment process to people who want to apply for benefits. Participants in the workshop were often not aware of their rights nor the choices that were available to them. This meant that some people turned to charities that provide advice for support with their application. Charity

staff may understand the person's situation and mental health problem well. However, people have told us that it can be difficult to arrange for the representative to be available, and even when they are, some assessors do not allow advocates to explain their conditions on their behalf. Other people did not have access to such support at all.

The solutions:

The DWP should provide a flow chart to illustrate the assessment process.

The assessment process could be made more accessible if there was a visual representation of what the steps are and how individuals will be allocated points during the assessment. This will prepare people for what lies ahead.

Shorter forms should be available for people who struggle with them, so they can instead focus on providing information during their assessment.

While the long forms work for some people who need the space to provide detail about their health, for others they are a significant barrier. Some people also don't have access to the medical evidence asked for. A shorter option could be offered for people who struggle with the form but could explain their health in an assessment setting.

The deadline to return forms should be extended to at least six weeks.

Some participants needed more time to fill forms in, pull together evidence, and seek support from loved ones or support services. Longer timeframes would help people to gather as much information and evidence as possible, to allow assessors to make fully informed decisions, and potentially reduce the need for further assessment or appeals. One participant suggested that people should have 6 weeks. At the beginning of the pandemic, people had 12 weeks, which was considered a helpful timeframe.

People should get confirmation that their form and additional documents have been received. This would allow people to feel more confident in the process and understand at which stage their application is as well as reduce worries about when they might be able to receive support.

There should be an option to request a preference for email or paper correspondence. As people's circumstances, skills and mental health vary, the correspondence type that works for them varies, too. A simple choice in communication method can help some people to better understand and engage with the benefits system.

There needs to be better access to advocates to be with the person during an assessment. People want advocates from charities or social services to be available to support them ahead of and during an assessment. This person should be allowed to talk to the assessor, with the person's permission, to better explain their issues. This would help people who struggle to explain their circumstances, and also help the assessor to come to a fair and well-informed decision. The DWP has suggested that they could test providing advocacy

support,¹⁰ but it is important to people that advocates are independent of the DWP.

The information stated on initial application forms and evidence submitted should be used by assessors. For people who have been able to provide detail and/or evidence in their forms, assessors should use this during the assessment. This would mean an initial process of verifying details and reviewing existing evidence. This could reduce the overall number of assessments as some people might qualify for benefits on the strength of their form and written evidence.

3. Assessment questions and criteria need to reflect the reality of mental health problems.

The problem: Participants were clear that the questions they were asked during their assessment were not always relevant to their mental health problems or how these affected them. As a result, the assessment process did not accurately capture the impact of their mental health. Some people were shut down by their assessor when they tried to explain the mental health impact on an activity the assessor interpreted as a physical matter. The issues were with the questions asked, but as questions are based on the criteria used to determine eligibility, this also reflects problems with the criteria themselves.

The solutions:

Assessors should take a more individualised approach to questions which help identify how people's mental health problems can affect them differently. Assessors should tailor their questions to the individual which means both open and closed questions might be required. The criteria also need to be updated to reflect more consideration of mental health problems.

Assessments should consider wider circumstances. The context in which individuals are living is important to identify what barriers or extra costs they may face, for example, the public transport available in their area or whether they have children. This needs to be reflected in the criteria and asked about.

Assessors should ask about longer timeframes, to take into account how mental health problems fluctuate. As mental health problems can fluctuate significantly, how assessments consider this is very important. Ideas from workshop participants reflected that depending on the person, different timeframes would be relevant. In general, it was felt that the timeframes need to be longer, looking backwards, including up to the last two years.

The WCA should consider how someone's health has been when they have had a job. It was felt that as the assessment considers whether someone can work, it should also factor in how a person's health can potentially deteriorate

due to being in work. This also highlights the need for questions to be more relevant to work, and the type of work available to the individual.

From the issues we heard about assessment questions and criteria, we believe the government needs to go much further. Reforming benefits criteria is an especially complicated issue, which is why we have argued this would be a key role of a commission led by disabled people to redesign assessments.

4. Fewer assessments should be carried out.

The problem: Participants told us that they had to repeat themselves when they first applied for benefits and were reassessed. Many people put a lot of effort into filling in forms and gathering evidence for their benefit claim, with the hope this would be enough to be awarded the benefit, or at least reduce what needed to be covered during an assessment. Instead, they found assessments went over the same ground as the forms. Some people struggled to get medical evidence and medical professionals' opinions, but, when they handed it in, felt that these were ignored. Not only did these experiences feel like a waste of time and resource, but added to the feeling that assessors didn't believe them and were trying to catch them out.

Some participants said forms should be shorter. Others were happy with long forms if it could reduce the stress of talking to an assessor for an assessment. But this potential benefit was removed if people were asked to repeat everything during the assessment.

Participants across workshops expressed that reassessing people with long-term conditions was unnecessary and time consuming for both parties. It meant they had to go through the stress of an assessment again and added to the insecurity in their financial situation. This insecurity made it hard for people to make progress on improving their mental health.

These experiences were more acute for people who applied for both PIP and ESA or UC and had to undergo multiple assessments and application processes. People didn't understand why they had to give the DWP the same information they had already given when applying for their other benefit.

The solutions:

The DWP should provide more help for people to gather evidence.

Participants wanted the DWP to do more to make sure healthcare staff could help people to get the types of evidence the DWP asks for and that this evidence focused on the benefit criteria. Although the capacity for work questionnaires for ESA and UC say that people should not gather new evidence, it felt important to many people that they have evidence to support their claim. If the DWP did more to support people to gather evidence, they could increase

the focus on the criteria so that more evidence could be directly used by assessors and decision makers.

The information stated on initial application forms and evidence submitted should be used by assessors. For people who have been able to provide detail and/or evidence in their forms, assessors should use this during the assessment. This would mean an initial process of verifying details and reviewing existing evidence. The overall number of assessments could be reduced through this approach as some people might qualify for benefits on the strength of their form and written evidence.

More benefit awards should be made based on medical evidence when it's available. The system needs to be flexible to what people are able to provide as evidence. When people can provide information, assessors and decision makers should use the forms and medical evidence people have submitted to grant someone benefits, without requiring them to then go through an assessment.

There should be better communication within the DWP to share information on individuals to make more benefit awards. Rather than having to give information about their health repeatedly, participants wanted the DWP staff to have access to the information already submitted. For example, evidence used for a PIP application could be taken on board when someone applies for UC. We know that the DWP is planning to build an integrated digital system for PIP, UC and ESA, which may be able to solve this. We have previously heard from people with mental health problems that merging PIP assessments and WCAs would not help, as this places too much financial risk on one assessment.

There should be longer between reassessments. This would reduce the stress people go through during reassessments and give people more security and space to focus on their mental health.

There should be lifetime awards for some people with mental health problems. For some people their condition will not improve, and successive reassessments serve only to increase stress and uncertainty. Lifetime awards could remove unnecessary stress for many people if they knew their benefits were secure. This could also improve some people's mental health and give them more independence.

5. Assessors need more mental health expertise and to be more understanding.

The problem: People with mental health problems told us they were usually assessed by people without specialist mental health knowledge and who showed little understanding of them, often making unfair assumptions. They also felt as

if they weren't believed, and the assessor was trying to find a way to demonstrate they should not be eligible for benefits.

Heather¹⁷ told us of being questioned by their assessor about how they got to the assessment centre and appeared to be making suggestions they couldn't be that unwell if they had made it there alone. Others told us about being judged on their appearance or for 'seeming intelligent'. People go through tremendous effort to be able to get to their assessments and to articulate how their mental health affects them. They told us they then felt penalised for doing so.

One person compared assessments to being put on trial and other participants agreed. It was felt that assessors were often looking for what someone can do, as a way to disprove the severity of their mental health or the need for benefits. Participants who were too unwell to work told us that they wished they were well enough to work. They were not trying to avoid work but felt they were treated as if they were.

Many people with mental health problems, even when they are significantly debilitating, do not have access to health services, and many others do not take medication. This may mean that they have no medical evidence to support their application.

We know that people who do not experience mental health problems can often struggle to understand what people with mental health problems go through. They can be very confused as to why someone simply does not get on with the tasks they need to carry out in daily life. When assessors take this attitude, they tend to dismiss the person sat in front of them. It appears that assessors often think that mental health symptoms are beliefs that need to be challenged and so underestimate their severity. This is both emotionally difficult for the person being assessed and, in many cases, negatively affects their mental health. It also appears to be a significant contributor to wrong assessment outcomes and high appeal rates.

The solutions:

All assessors should be required to have mental health qualifications and/or receive mental health awareness training and understand the barriers people with mental health problems face when it comes to assessments. Participants felt that all assessors should have mental health qualifications as mental health problems are so common among people applying for benefits. This would be either a requirement to apply for a role as an assessor, or part of the training when they become an assessor. In either case, they should have training which covers the barriers people with mental health problems face and the ways mental health can fluctuate.

Assessors should be allocated to an individual to line up their specialty with the person's condition. Assessors are health care professionals who have

a variety of backgrounds. Some have more mental health expertise than others but many have little or no understanding. If assessors with mental health specialisms were allocated to assess people with mental health problems, people could end up with more accurate assessments.

The approach of assessors needs to change so there is a greater focus on supporting people to explain their health rather than trying to catch them out. Participants said that the starting point for assessors should be that they believe the individual, and their primary role should be to help people to give details about their health. It was suggested that the principles of their approach should be: sympathetic, trusting, respectful and caring.

Assessors should be accepting people's accounts of their mental health, and the testimony of individuals within their assessments must be taken more seriously by decision makers at the DWP. When personal testimony is all a person has as evidence, the system must allow for this to be enough.

Assessors need to understand cultural differences. Assessors need to be able to understand how people from different ethnic backgrounds and cultures may speak differently about their mental health or may have different experiences of their mental health.¹⁸ Otherwise, there is a danger of making assumptions about what someone means, or not recognising when they need to ask more questions to get information, particularly when someone may be reluctant to talk about their mental health due to stigma.

6. The accountability of assessors and decision makers needs strengthening.

The problem: The assessment outcomes often didn't make sense to the workshop participants, not fitting with their experience of their mental health or their assessment. Some people who subsequently requested their assessment reports found that substantive mistakes had been made or there were significant discrepancies.

Richard told us his report said he'd made eye contact when he hadn't. Another workshop participant, Jess, found her assessor to be nice and understanding which made her feel hopeful about the process but noticed that they weren't asking relevant questions to her condition. When she later requested her report, she discovered that what the assessor had written down was completely different to what she had told them.

People felt that assessors got away with lying or making mistakes, and that this was an intentional part of the system. Some wondered whether assessors face consequences if they repeatedly make mistakes, or if these mistakes are usually not discovered, given that people don't always know they can request a copy of their report. Most people in our workshops didn't know they could have their

assessments recorded. One person told us that he had asked for his assessment to be recorded but didn't know he had to give three days' notice, so he had to record it himself on his mobile phone.

Participants observed that typing and listening at the same time was a lot to ask of an assessor and was likely to lead to inaccuracies in reports. These mistakes then affect the decisions made about people's benefits entitlements, which have life changing consequences.

The solutions:

Providers should automatically record assessments and send out a copy of the assessment report. Currently, requests must be made to have an assessment recorded, to get a transcript, or to receive a copy of the assessment report. However, many people aren't aware of how to navigate these processes or are too unwell to engage with them. Participants suggested an opt-out process should be established for assessment recordings, with the default being to record assessments and send out reports so that people have access to the evidence of the assessment and the assessor's account of the assessment. It was also felt that this could improve the quality of assessments and increase accountability, as assessors would know these would be sent to the individual.

There should be higher requirements for the performance of assessors, with an independent panel of disabled people to quality assure how assessments are being carried out. It was felt that assessments would also be improved if the performance requirements of assessors were increased. Assessors' work should be held to a higher standard, in terms of quality and accuracy of assessment reports, and checks on these increased. Many people felt that assessors lacked accountability or repercussions if reports were inaccurate or wrong decisions were made. To avoid this, and to ensure the DWP is always operating fairly and effectively, it was suggested that assessments should be overseen, or quality assured by disabled people with experience of going through the benefits system.

What our findings mean for UK government reform

The problems with assessments which were discussed in our workshops were all issues we had sadly heard about many times from people with mental health problems. We detailed many of these in our report, *People, Not Tick-boxes* (2020), in which we also explored the inaccuracy of many assessments. Our polling shows that these issues are not rare experiences, but common among people with mental health problems going through assessments.

Some issues were noted in *Shaping Future Support: The Health and Disability Green Paper* (2021) published by the DWP.¹⁰ In the Green Paper, the DWP said they wanted to reduce the number of unnecessary assessments, offer greater flexibility, and provide more support to people going through the system. They were also considering whether changes were needed to the assessment criteria. Our evidence suggests that these changes are needed. However, the Green Paper does not address the underlying assumptions on which the benefits system is built or the DWP's approach to disabled people.

Within most of the experiences we heard about was the feeling that the benefits system, and the individuals working within it, were trying to catch people out. Rather than a system designed to support people, the experience was of a system trying to find ways to avoid giving support, a system preoccupied with the assumption that people without a health problem or disability were trying to claim health-related benefits, or people who were disabled were trying to get out of working. In fact, the people with mental health problems who we spoke to and who each faced huge barriers to work, all wished that work was a possibility for them. The DWP needs to shift its balance away from gatekeeping benefits towards providing support to disabled people.

The DWP has proposed that the assessment for employment support for disabled people should focus on what people can and could do, rather than what they can't.¹⁹ We are concerned that such an assessment would be based on theoretical situations, where the barriers someone faces are removed, without evidence that this will be possible. The current WCA is used to determine the level of financial support someone receives and whether they are subject to conditionality and sanctions. Such an assessment must allow people to talk about the barriers they face and look at why they need financial support. We are concerned that an assessment based on what someone can do would be used to justify not giving someone the required level of financial support or to apply conditionality to them, when they are too unwell.

The DWP can still do more to support people with mental health problems to explore if they can work. However, this should not be part of an assessment, and would only work if people can truly trust that the DWP will not use the information to deny them access to benefits or commit them to sanctionable activities. We know people are often given conditional activities to do that they

are too unwell to undertake because of the inaccuracy of their assessment and a lack of understanding from Work Coaches.²⁰ This risks their benefit entitlement and worsens their mental health problem as they are sanctioned if they do not perform these activities. People must be given security in their income, with conditionality removed so they can trust the DWP to support them and have an open conversation about support to be able to work.

The DWP has been concerned for some time about the lack of trust disabled people have in it. For disabled people to trust the DWP, the department needs to show trust in disabled people, too. This will take time, and fundamental reform. The DWP must change its approach within the assessments system, and its conditionality regime. To truly foster mutual trust, the DWP must give disabled people a real say in how the system is reformed.

Conclusion and recommendations

Our research has shown that people with mental health problems face many issues in the benefits assessments system. They face unacceptable barriers to getting the benefits they are eligible for, and they are mistreated by the system which is supposed to be there to provide them with financial security. This cannot be allowed to continue. Our workshop participants had many ideas for how assessments can be improved. Their experiences demonstrate the need for reform and the direction of change that is needed.

People with experience of the benefits system must be at the heart of how to improve it.

The UK government should:

- 1. create a new commission – one that is led by disabled people** with experience of the benefits system. It should be tasked with proposing reforms to the structure and criteria of benefits assessments. The commission must be given the time and resources to consult widely with experts and other disabled people and make detailed recommendations. It should propose new criteria and questions for the PIP assessment and WCA, which better reflect how a person's health condition or disability affect their everyday life, their extra costs, and their barriers to undertaking paid work.
- 2. establish an independent regulator for the benefits system** to hold the UK government to account, protect the rights of disabled people, and enforce improved assessments. A regulator would inspect the work of assessment providers, reviewing assessment recordings and reports, as well as the work of decision makers in the DWP. It would have the power to compel evidence from the DWP and produce reports with recommendations that must be taken forward. It would monitor how well the DWP is fulfilling its duties under the law, protecting the rights of people applying for benefits, and living up to the values of dignity and respect which should underpin health assessments for benefits.

Nearly every other major public service has a system of independent regulation. Ofsted and the Care Quality Commission, for example, play crucial roles. Though these systems are not perfect, they are able to obtain information and carry out inspections available to no other body. The benefits system desperately needs such oversight.

In the meantime, while these larger reforms are being developed, there are 6 recommendations for immediate action which will go some way to improve the current benefits assessment system:

1. People should be able to choose their assessment method and time.

2. The process should be easier to navigate.
3. Assessment questions and criteria need to reflect the reality of mental health problems.
4. Fewer assessments should be carried out.
5. Assessors need more mental health expertise and to be more understanding.
6. The accountability of assessors and decision makers needs strengthening.

For these reforms to be successful and have a positive impact, the DWP needs to shift the priorities underlying the benefits system. It needs to move away from a system focused on gatekeeping benefits and threats of sanctions, to one which is focused on providing support.

Endnotes

¹ 'I did not agree with the outcome so I appealed against the decision' and 'I did not agree with the outcome but I didn't appeal it' answers combined.

² 'Somewhat agree' and 'Somewhat agree' answers combined.

³ Department for Work and Pensions (2023). Stat-Xplore: PIP Cases with Entitlement. Available at: <https://stat-xplore.dwp.gov.uk/>. 36.85% of people receiving PIP in October 2022 had 'psychiatric disorders'.

⁴ Department for Work and Pensions (2023). Stat-Xplore: ESA Medical condition by Quarter and Employment and Support Allowance Caseload. Available at: <https://stat-xplore.dwp.gov.uk/>. 50.74% of people receiving ESA in August 2022 had 'mental and behavioural disorders' based on the International Classification of Diseases.

⁵ Department for Work and Pensions (2022). Personal Independence Payment statistics to October 2022. Available at: <https://www.gov.uk/government/statistics/personal-independence-payment-statistics-to-october-2022>

⁶ Ministry of Justice (2022). Tribunal Statistics Quarterly: July to September 2022. Available at: <https://www.gov.uk/government/statistics/tribunal-statistics-quarterly-july-to-september-2022>. 70% of 32,871 tribunal hearings for PIP in 2021/22 saw the decision overturned in favour of the claimant.

⁷ Department for Work and Pensions (2022). Written questions, answers and statements: Personal Independence Payment: Tribunals, UIN 42121. Available at: <https://questions-statements.parliament.uk/written-questions/detail/2022-07-21/42121>

⁸ Ministry of Justice (2022). Tribunal Statistics Quarterly: July to September 2022. Available at: <https://www.gov.uk/government/statistics/tribunal-statistics-quarterly-july-to-september-2022>. 59% of 3,106 tribunal hearings for ESA in 2021/22 saw the decision overturned in favour of the claimant.

⁹ Mind (2020). People, Not Tick-Boxes: A call to rebuild the disability benefits system. Available at: <https://www.mind.org.uk/media/6483/people-not-tick-boxes-october2020.pdf>

¹⁰ Department for Work and Pensions (2021). Shaping Future Support: The Health and Disability Green Paper. Available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1004042/shaping-future-support-the-health-and-disability-green-paper.pdf

¹¹ Department for Work and Pensions (2022). PIP Assessment Guide: Part One - The Assessment Process. Available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1092460/pip-assessment-guide-part-1-assessment-process.pdf

¹² Department for Work and Pensions (2022). Guidance: Universal Credit: Health conditions and disability guide. Available at: <https://www.gov.uk/government/publications/universal-credit-if-you-have-a-disability-or-health-condition-quick-guide/universal-credit-if-you-have-a-disability-or-health-condition>

¹³ "Strongly disagree" and "Somewhat disagree" answers combined.

¹⁴ 71% of respondents who did not agree with the outcome of their assessment strongly disagreed or somewhat disagreed with the statement 'I felt that my benefits assessor understood mental health problems'.

¹⁵ Either strongly disagreed or somewhat disagreed with the statement 'I felt that my benefits assessment took into account my mental health problems'.

¹⁶ Age UK (2020). IAPT and mental health in older people. Available at: <https://www.ageuk.org.uk/discover/2020/01/iapt/>

¹⁷ Pseudonym used to protect anonymity.

¹⁸ Mind (no date). What is diversity and difference? Available at: <https://www.mind.org.uk/workplace/influence-and-participation-toolkit/how/planning/diversity-and-difference/>

¹⁹ Department for Work and Pensions (2021). Shaping Future Support: The Health and Disability Green Paper. Available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1004042/shaping-future-support-the-health-and-disability-green-paper.pdf

²⁰ Parkes, Henry (2022). No-one Left Behind: Supporting People with Complex Needs on Universal Credit. Available at: <https://www.ippr.org/files/2022-04/no-one-left-behind-march22.pdf>



Reassessing assessments: How people with mental health problems can help fix the broken benefits system.

Written by Charlotte Furber
Published by Mind

Mind
2 Redman Place
London
E20 1JQ

www.mind.org.uk

Registered charity number 219830