

## **Money and Mental Health's submission to the Equality and Human Rights Commission's investigation and assessment into the Secretary of State for Work and Pensions**

### **Introduction**

The Money and Mental Health Policy Institute is a research charity established by Martin Lewis to break the vicious cycle of money and mental health problems. We aim to be a world-class centre of expertise developing practical policy solutions, working in partnership with those providing services, those who shape them, and those using them to find out what works. Everything we do is rooted in the lived experience of our Research Community, a group of 5,000 people with personal experience of mental health problems.

This response draws on our wider body of research. Unless otherwise specified, all quotes in this response are drawn directly from the Research Community.

### **Background**

Under Section 20 and Schedule 2 of the Equality Act 2010, service providers or those exercising a public function must take reasonable steps to avoid disabled people being put at a substantial disadvantage compared with people who are not disabled. This could be done by: changing provisions, criteria or practices (for example, changing a policy); changing or removing a physical feature or providing a reasonable alternative way to avoid that feature; or providing auxiliary aids. An adjustment should, as far as possible, remove or reduce any disadvantage faced by a disabled worker or service user.

The Equality and Human Rights Commission suspects that the Department for Work and Pensions (DWP) may have failed to anticipate and make reasonable adjustments for disabled people with a mental impairment during health assessment determinations for Employment and Support Allowance (ESA), Universal Credit (UC) and Personal Independence Payment (PIP).

In our response to this investigation, we outline some of the common experiences members of our Research Community have had when requesting reasonable adjustments for health and disability benefit assessments in the period from January 2021.

### **Q.18 Tell us about your experience**

In July 2024, Money and Mental Health surveyed 157 members of our Research Community about their experiences of requesting reasonable adjustments for health and disability benefit assessments. Of those 157, 95 had attended an assessment for UC, ESA and/or PIP since January 2021 and identified as having a 'mental impairment' as defined by Section 6 of the Equality Act 2010.

We asked these 95 people to recount their experiences of the DWP failing to make or anticipate a reasonable adjustment in light of their mental health problem for a health and disability benefit. Below we have outlined the key themes and experiences that came out of this research, to exemplify the common challenges respondents had, and what the impact of these were.

#### A lack of accessible assessment channel

For some members of our Research Community, attending a face-to-face assessment is too challenging because of the difficulties they face leaving their home or travelling on public transport. For others, a telephone assessment is impossible given the difficulties they face using the phone. While applicants are able to request to have their assessment via a specific channel or as a home visit, we have heard experiences where these requests have not been granted.

*“Despite my agoraphobia, they [the assessment provider] refused a home visit, or a remote over the phone visit in January 2021. It was so hard to deal with having to travel outside of my home.”* Expert by experience

*“I requested a home assessment which I had been allowed for UC WCA but was only offered a video assessment. As I have severe anxiety, OCD and chronic depression, this was far from ideal. I have no affinity for tech and this was an added stress during the interview. I have not left the house in 3 years except for one disastrous, panic stricken GP appointment so I felt a home visit, whilst still scary, was justified.”* Expert by experience

*“DWP refused me a home visit and did a telephone call where the assessor could not see the distress I was under. I had to request on a number of occasions throughout for them to stop as I was so upset. I even considered stopping the whole interview and withdrawing my claim.”* Expert by experience

Respondents also spoke about how assessment centres could be inaccessible or negatively affect their mental health. While assessment providers say applicants should tell them if this is the case, and that they will see what they can offer, we heard of instances where no adjustments were made in light of this.

*“With my ESA assessments they made me wait in a waiting room with loads of other people knowing that I had severe social anxiety.”* Expert by experience

These examples demonstrate assessors’ failings to adhere to Section 20 and Schedule 2 of the Equality Act 2010. In particular, their failure to change provisions so people with mental health problems can access and attend assessments without being placed at a disadvantage compared to people without such conditions. To ensure compliance with the Equality Act, assessors should always grant requests to carry out assessments via a specific channel when other channels would prove harmful to someone’s mental health. More broadly, assessors

should review their communications so people are not threatened with having their benefits cut if they don't attend a face-to-face assessment.

*"They threatened to take my benefits off me if I was unable to attend a face to face assessment when I asked for either a home or telephone one & got told I'd got to go in for it." Expert by experience*

DWP and assessors should also look to make provisions in line with the Equality Act so assessment centres themselves are more accessible for people with mental health problems. This could include making it easier for people to request a taxi to and from an assessment centre given the challenges people with mental health problems can face using public transport; and making assessment centres more welcoming, friendly spaces that don't cause undue stress or anxiety. More generally, the DWP and assessors should also make sure people don't have to travel long distances to attend an assessment.

*"I want to be able to request a taxi without being told that I had to go through multiple processes such as finding a quote, getting approval." Expert by experience*

*"Assessments should be close to home rather than having to travel on a train for 30-45 minutes or on a bus for an hour or so. You should be given a choice as to what type of assessment you want rather than DWP demanding you must travel however far to an assessment centre." Expert by experience*

*"The assessments could be held at the wellbeing/places of care, so that it's less worrying for the person being assessed." Expert by experience*

#### Assessments not being provided at the preferred time

As well as granting people the option to have an assessment via their preferred channel, it's also important that people can request to have these at specific times. This can be especially important for people with mental health problems, who can face challenges participating in assessments at specific points of the day due to the effect of medication and fatigue, for example. Allowing individuals to choose time slots would also make it easier for people who would like advocates or social workers to attend, enabling them to coordinate appointments with their availability.

*"For both PIP and ESA assessments I asked for them to be done on the phone and in the afternoon/evening. Both requests were refused and I was given a 9am appointment for PIP assessment and 9.20am for ESA. After several calls I managed to get the PIP assessment changed to a phone call but they refused to change the time. I didn't get up in time due to taking sleeping pills, I made them aware of this when I filled in the review form. My payment was due 3 days after the assessment and they stopped it saying I didn't attend the*

*assessment. I had to get my support worker to call them but it still took 3 weeks to get the payment back. This happened in November 2023.” Expert by experience*

#### Insufficient communications about rearrangements

Members of our Research Community were also frustrated when assessments weren't punctual, with some respondents having to wait hours after the specified time until their assessment. This can be especially anxiety inducing when people aren't notified about the delay.

*“For the WCA the assessor did not call on time and then rang me later in the afternoon to apologise for not keeping appointment on time. This caused me extensive anxiety as I was unsure if the assessor was going to call at all.” Expert by experience*

A number of respondents also had their assessments rescheduled at the last minute. Changing the date and time of assessments at such late notice can be especially triggering for people with mental health problems, who can require a lot of mental preparation in anticipation of an assessment.

We would therefore urge assessors to consider changing their practice so any delays or re-arrangements to assessments are communicated to applicants with as much notice and warning as possible. This would help prevent people with mental health problems being put at a disadvantage, as members of our Research Community can be very anxious and struggle to express themselves in an assessment after such a delay.

#### A lack of flexibility with deadlines

Members of our Research Community routinely struggle with the lack of flexibility around deadlines. Despite common symptoms of mental health problems such as low motivation, reduced concentration and memory problems making it hard to complete forms in time, we often hear of instances where the DWP fails to exercise flexibility concerning deadlines.

*“I understand the need for deadlines, but 3 weeks wasn't enough time. People who are ill with general anxiety disorder and major depression should be clearly informed about exactly why a re-assessment is required and what is going to be re-assessed, then given at least 6 weeks to complete a huge form like the UC50.” Expert by experience*

The DWP should better anticipate the needs of people with mental impairments by being flexible about deadlines, given the challenges this group can face completing forms. In terms of practice, it's also important that applicants are given enough notice in advance of being called for an assessment, which can be especially important for those with mental health problems who might need longer to mentally prepare in advance on an assessment.

*"I wish they provided more flexibility on deadline dates for returning the form and incorporated extensions for those who may struggle." Expert by experience*

*"Last time I got a call out of the blue - no warning, no time or date given. Just a cold call." Expert by experience*

### Insufficient provision of breaks

Respondents frequently spoke about the fact that assessments can be inaccessibly long, which can be compounded by a lack of breaks. For people with mental health problems who can face challenges with energy and concentration, this can make it very hard for them to articulate and communicate their experiences throughout the course of the assessment. Respondents' experiences suggested there is often very little consideration or adjustment made in light of this.

*"It was a long chat...after an hour and a half I was very tired and desperate for the loo. The assessor threw in a quick fire round of questions, I misheard him as I was going into the hall for the loo and started wetting myself. I said yes, he said that's all, and that he'll send the report to the DWP. He said goodbye and rang off. After I sorted my pad and wet clothes I realised I had chosen the wrong answer and tried to ring him back, but it was a number withheld. I'm now very upset as I gave the wrong answer to get him off the phone and stress, anxiety and confusion had set in after such a long call." Expert by experience*

*"I had a phone PIP assessment a few months ago. I had no support offered in relation to my disability and mental health conditions. The assessor knew I had ADHD and as a result would struggle to focus. Despite this, the assessment went for 1.5 hours without any breaks." Expert by experience*

To avoid people with mental health problems being put at a disadvantage during the assessment process, assessors must make the length of assessments more manageable to people with mental health problems. They must also routinely communicate and provide the opportunity for breaks.

*"DWP shouldn't push hour and half long calls on me, I felt it was all too much even though he was very nice and chatty. But we talked so much I started brain-fading, it all unravelled after 50 mins." Expert by experience*

*"I wish they would consider the fact that my mental health conditions might mean that I need breaks to be able to complete the phone assessment properly and accurately." Expert by experience*

*"I don't think an assessment should be longer than an hour as they are exhausting, stressful and gruelling." Expert by experience*

More generally, it's also important that assessors don't rush people through the assessment process, and give people enough time to explain their situation and articulate their experience.

*"I would have liked to have a break from questions or to answer the questions properly. I was rushed through everything with no time to process information." Expert by experience*

#### Not recording or providing transcripts of assessments

Despite people being able to request to have their assessment recorded, with a copy provided in follow-up, a number of respondents told us that the DWP had refused this when it came to the assessment.

*"For my DWP ESA health assessment this year I requested that the call be recorded. Not just to back up my memory but also to provide witness to what I was being told. I gave a week's notice as requested. On the day of the telephone interview I asked for confirmation that this and the interviewer (who was kinder and more human than most in my experience with health assessments) told me that there was no record of recorded interview being requested and if I wanted to get it recorded we would have to rebook for 3-4 weeks time. Given the stress from anticipating the interview I decided to go ahead without the recording." Expert by experience*

*"PIP assessment - I asked can I record the phone call in advance and they said no twice so I recorded my assessment myself." Expert by experience*

It's important that when this is requested, people's assessments are recorded and applicants are provided with a copy of this. Ideally, we believe assessments should be recorded as default, with an opt-out option available.

#### Disallowing advocates

A number of participants also cited how they need support when attending health and disability benefit assessments. For some, having advocates or friends there to assist them was the difference between being able to attend an assessment and convey how their condition affects them or not. However, some respondents' advocates had not been allowed in the assessment, or were not allowed to speak or weren't listened to, all of which is contrary to the assessment guidance.

*"At my PIP assessment in March 24 I brought my friend on the call as my advocate. She was told by the nurse carrying out the assessment that she was not allowed to talk on my behalf. My friend had to quote back the guidance given by the DWP cover letter that she was allowed to if I was struggling to recall or too overwhelmed as I was on the call." Expert by experience*

*“Now on the 4th appointment as the previous 3 cancelled one as assessor off sick and the others because they said they couldn't talk to my appointed advocate who has always dealt with them. I can't talk on the phone and have to drive up to 4 hours to get to her house for 8am and 9am appointments only to be told they won't carry on assessment. The stress and travelling has me on my knees.” Expert by experience*

In line with the Equality Act, the DWP must routinely communicate that applicants can have advocates at the assessment, while allowing these advocates to speak in the assessment and listen to their contributions.

*“DWP must give the option for phone or in person as well as the ability to take someone I trust with me to provide support and help answer questions. They state this is okay however I know of those who have been refused this at the door and have been told they must complete assessments alone.” Expert by experience*

#### Not responding to safeguarding concerns

We also received one very concerning report from a respondent who had raised a safeguarding concern during an assessment that was not adequately responded to by the DWP.

*“It was around Feb/March 2022. It was an over the phone assessment for PIP. I am unsure who was doing the assessment. However, I was in a crisis. Halfway through the call, I broke down and admitted I'd hoarded serious amounts of my mother's medication ready to take an overdose. The assessment continued! Only looking back now I can't believe it continued. I was seriously suicidal and had actively taken steps to prepare for suicide. The assessor was the first person I'd told. The assessment continued.... Afterwards they did contact my doctor but really for the assessment to continue is astounding...I think a basic reasonable adjustment is if someone disclosed steps they've taken to end their life, an assessment is stopped and the relevant medical team should be contacted straight away.” Expert by experience*

We have previously outlined our concerns about the DWP's inadequate process for identifying and responding to safeguarding concerns in our response to the Work and Pensions Select Committee's inquiry

[<https://www.moneyandmentalhealth.org/wp-content/uploads/2023/10/Money-and-Mental-Healths-submission-to-the-Work-and-Pensions-Committees-inquiry-into-safeguarding-vulnerable-claimants-.pdf>]. If the DWP is to stop putting disabled people at a substantial disadvantage compared with people who are not disabled, it's vital that their processes for identifying and responding to vulnerability and safeguarding concerns are improved.

#### Routinely offer reasonable adjustments

Finally, a recurring point made by respondents was that reasonable adjustments need to be routinely offered before assessments. Members of our Research Community are often unaware

of what adjustments they can request, and how to request them. Key to the DWP better anticipating and meeting the needs of people with mental health problems is them routinely communicating and offering adjustments to applicants in anticipation of events like health and disability benefit assessments.