

People, Not Tick-Boxes

A call to rebuild the disability benefits system

We're Mind, the leading mental health charity in England and Wales. We're here to make sure anyone with a mental health problem has somewhere to turn for advice and support. We work for a better deal and respect for everyone experiencing a mental health problem

People, Not Tick-Boxes:
A call to reform the disability benefits system

Written by Ayaz Manji Published by Mind

Mind 15-19 Broadway Stratford London E15 4BQ

Charity Number: 219830.



Contents

| Executive summary | 4 |
|---|----|
| Introduction | 6 |
| Section 1: Making fair and accurate decisions | 8 |
| Section 2: Giving people security | 11 |
| Section 3: Giving people choice | 14 |
| Section 4: Asking the right questions | 17 |
| Section 5: Taking the fear out of the system | 21 |
| Conclusion and next steps | 24 |

People, Not Tick-Boxes

3

Executive Summary

When you become unwell, the last thing you need is the risk of being left without enough money to live on or a roof over your head.

But in producing this report we heard from too many people with mental health problems who have faced homelessness, destitution and mental health crisis because of problems with their benefits. People who spent months of their lives challenging decisions which were made on the basis that they could make eye contact with their assessor, or that they weren't taking the right kind of medication. People who were repeatedly forced to recount experiences of self-harm, trauma, and suicide attempts in each new encounter with the benefits system. These stories reflect what we hear every week from the people who contact us looking for support. They are not the exceptions or rare cases. This is the new norm. It's wrong and it needs to be put right.

"I have bipolar disorder and chronic anxiety. This has affected me for many years. This is my third assessment in the last four years. All I can say is my mental health has deteriorated since these assessments started. I literally lived in fear of the letter arriving. I find the questions on the form utterly degrading and hate that I can't fit into those boxes. They also bring about a deep sense of shame about not working. I was always ambitious, actually studying for a degree in social work before I was diagnosed, as well as working and doing volunteering. I became so low with this most recent assessment that I was seriously considering suicide as a way out. I found it unbearable." Nadia

"I stopped spending money on food and heating to save for an uncertain future, and relapsed terribly with anorexia. I had to give up my voluntary work and go into hospital as I was physically and mentally very unwell. The admission lasted a year - costing hundreds of thousands of pounds which I feel terribly guilty about. But if I had felt more supported to take recovery at my own pace, and not feared financial repercussions and sanctioning, then I do not think (nor do my medical team) that I would have relapsed at that point." Louisa

The benefits system has the power to transform people's lives. With the right help, people with mental health problems can get the security they need to move forward with their lives, to build connections with other people, and to live more independently. Far too often the system we have now fails to meet that promise. Politicians and policymakers need to show leadership and commit to building something better.

This report

This report sets out the case for five solutions designed to change the culture of the system. While our starting point has been the experiences of people with mental health problems, these proposals should improve the experiences of anyone who needs support from disability benefits. They are informed by conversations with people with mental health problems, by surveys of hundreds of people going through the system, and by a review of the existing evidence.

Making fair and accurate decisions

At the time of writing, seven in ten decisions for disability benefits which reach appeal are overturned. The most common reason for this is problems with the quality and accuracy of assessments. But the benefits system is nearly unique among UK public services in not having a regulator to provide oversight. We want to see the UK Government establish a new independent regulator for the benefits system. It would inspect the centres where assessments take place and where benefits decisions are made. It would have the power to seek information from the Department for Work and Pensions and to publish reports which hold them to account. When needed, it would take action to protect people's rights. It would be tasked with making sure that disabled people's testimony is recorded fairly and accurately, and that DWP processes do not put people at risk of harm when they apply for benefits.

Giving people security

We hear time and time again that the frequent use of face-to-face assessments can make people more unwell. People in very vulnerable circumstances are forced to recount traumatic experiences at every stage of the assessment process. While some people can have reassessments for Personal Independence Payments (PIP) or the Work Capability Assessment (WCA) switched-off altogether, there is still a lack of transparency over this process. We want to see the UK Government end the cycle of repeat assessments by giving disabled people clear routes to apply for lona-term or indefinite awards. This must include the right to challenge and appeal short-term awards.

Giving people choice

During the coronavirus pandemic the Department for Work and Pensions started offering telephone assessments for disability benefits. Some people have told us that being able to avoid face-to-face assessments has significantly reduced the pressure they face. But others have struggled to take part over the phone and risked being locked out of their benefits as a result. The UK Government should give people choices over the method of their assessment so that that everyone applying for benefits has the chance to put their case across and get a fair hearing.

Asking the right questions

People tell us that the questions they're asked during assessments don't reflect the reality of living with a mental health problem. Yet so far there has been little consensus about what a reformed assessment system could look like for both PIP and the WCA. We know that the starting point needs to be listening to disabled people about their own lives. We're calling for the UK Government to create a new commission tasked with recommending proposals to reform the structure and criteria of both assessments. This commission should be led by disabled people with experience of the benefits system and it should work with disabled people to produce its recommendations.

Taking the fear out of the system

There is now established evidence that the threat of sanctions does not help disabled people move closer to work. Some of that evidence comes from the Department for Work and Pensions (DWP) itself. People with mental health problems tell us that the pressure of attending Jobcentre appointments can become unmanageable, damaging their health and moving them further away from work. Sanctions affect the entire culture of the employment support system. Jobcentre staff are required to prioritise carrying out compulsory appointments and so aren't given the time to listen to people with mental health problems and to build trust. We need to see the UK Government end the use of sanctions for disabled people and for anyone waiting to go through assessments.

Introduction

When people get the right support from benefits it can be lifechanging.

Each year there are nearly 700,000 claims to disability benefits like Employment and Support Allowance (ESA) and Personal Independence Payments (PIP) made by people with mental health problems. When things go right, those benefits mean that people who are unwell can get the security they need to focus on moving forward with their lives, to build connections with other people and to live more independently.

Tess's story

Tess lost her job after her anxiety started to make it impossible for her to leave the house and to be out in public. After struggling to cope for several months, she told us that getting the outcome of her Work Capability Assessment (WCA) felt like she was getting her life back. She finally had the peace of mind that came with having a secure income. After a long wait she's finally getting help with her mental health and is starting to feel more confident about leaving the house. When she spoke to us, she was hoping to start training to be a counsellor. She described her benefit award as a lifeline, something that allowed her to start to rebuild and take things at her own pace.

But too often the process of trying to get that help is making people more unwell. In 2015 we worked with YouGov to survey more than a thousand people with mental health problems about the things that made a difference to their health. Of those who had considered or attempted suicide, nearly a third said that the fear of losing benefits was a factor.² There is no evidence to indicate that things have got any better since this time.

Steven's story

Steven has experienced depression, anxiety and psychosis for the last fifteen years. He often has panic attacks if he has to meet unfamiliar people and he hears voices which are threatening and abusive. When he received the letter telling him his Disability Living Allowance (DLA) was ending, he said he felt unable to cope with the thought of a face-to-face assessment for PIP. Hours after the assessor left his house, Steven self-harmed. He told us that in the days following the assessment he began to hear voices more frequently and more intensely. His application for PIP was successful but he is already dreading the prospect of another assessment in two years' time.

MPs from across parties have recognised that the assessment system for PIP and ESA needs to change. The cross-party Work and Pensions Committee concluded that 'failings in the processes—from application, to assessment, to decision-making and to challenge mechanisms have contributed to a lack of trust in both benefits' which 'risked undermining their entire operation'.³

We need to see politicians and policymakers show leadership to put this right. This report is an attempt to put people with mental health problems' voices at the heart of designing a new, fairer and more compassionate system.

This report

This report isn't a comprehensive roadmap for fixing all the problems that people with mental health problems experience when applying for benefits. And we know there are many problems that need fixing - from cuts to incapacity benefits to unnecessary hurdles with the Universal Credit application process. But in this report we focus on setting out the case for five fundamental reforms to the benefits system based on our conversations with hundreds of people with mental health problems and a review of the existing evidence. These calls to action are a starting place for building a system based on principles of dignity and respect.

People with mental health problems are not alone in struggling to navigate a benefits system that's not set up to meet their needs. Many of the people we hear from need support from the benefits system because of the combined impact of different impairments. The five calls to action in this report have started from the experiences of people with mental health problems but they are intended to improve the experience of anyone making a claim for disability benefits.

Methodology

This report presents new qualitative analysis of a survey carried out in July 2019 with 285 people with experience of mental health problems and who have applied for PIP, ESA or Universal Credit in the past two years. It also draws on Mind's 2017 survey of 843 people with experience of claiming PIP, and our 2019 survey of 124 people with experience of claiming Universal Credit.

Section 3 of this report draws on insights from ten in-depth interviews with people who have been through remote benefits assessments during the coronavirus pandemic.

Section I: Making fair and accurate decisions

Kate has experienced depression, anxiety and obsessive-compulsive disorder for most of her life. After experiencing a mental health crisis, she found her anxiety became more severe until she was no longer able to stay in her job. She applied for Employment and Support Allowance (ESA) and her claim was successful. But after a reassessment last year Kate was unexpectedly found fit-for-work despite nothing having changed about her circumstances.

When Kate requested the notes from her assessment, she found herself reading an account of the conversation that she didn't recognise. Her assessor wrote that she left the house every day, when Kate had said that she did so at most once a fortnight. To Kate, almost every detail that her assessor had noted about her daily routine seemed as if it was written about another person entirely. Something had clearly gone wrong.

It took Kate several months to get her decision overturned. She wrote a detailed letter explaining every inaccuracy in the report. She went through her old letters from her therapist and made copies of each one. She visited her GP and asked for another detailed statement about how her mental health affected her and asked her mother to do the same. Eventually she was able to convince the decision-makers at the Department for Work and Pensions (DWP) to change her outcome before it reached appeal. But the toll the whole process took on her has been a major setback to Kate's health. And she still doesn't understand why it happened.

Kate isn't alone in this. At the time of writing, seven in ten decisions for disability benefits which reach appeal are overturned.⁴ A 2012 pilot run by the DWP looked at the reasons why disability benefits decisions were overturned by the courts:

- 41% of decisions were overturned because
 the courts heard more 'cogent oral evidence' —
 evidence that likely would have been available
 to the person first carrying out the assessment
 if they had asked the right questions and
 recorded the answers in detail.
- A further 15% were overturned based on 'substantially the same facts' that were available to the Department when they made their first decision.

 Only 8% of decisions were overturned because the courts were able to see new documentary evidence, for example medical reports.⁵

Clearly something is going wrong in how decisions about benefits are made.

What people with mental health problems told us about the accuracy of assessments

The most frequent problems that people with mental health problem raised with us were inaccuracies in their assessment reports. These included reports which omitted significant details as well as reports which seriously mischaracterised what took place during the assessment.

"I had a face to face assessment and, having read through the notes made at the assessment, I can honestly say that most of them were completely inaccurate. The assessor claimed I had made statements that I definitely did not make, that I did several things during the day that I never do. They said that I leave my house every single day when it's actually fortnightly at most. They had invented an entire daily routine for me that I didn't have! It was all completely false, and I don't know where this information came from, because it wasn't from me." Kate

"I was having an anxiety attack during the assessment. I had chest pains and was sweating profusely with pins and needles in my arm. The person didn't seem particularly bothered how I was presenting and indicated on report I was "mildly anxious". The report came back with so many inaccuracies it was ridiculous. It had no mention that I had a support worker with me, and because I drove my daughter to school, I was deemed fit." Liz

Other people pointed to the use of 'informal observations' in their reports. For example, assessors had noted whether they were able to make eye contact or whether they were 'well-dressed'. It's not clear what weight these observations were given in determining each person's outcome, but the fact that they were included in assessment reports cast doubt on the fairness of the whole process.

"They had ignored all the things I said, and the evidence provided by health professionals. They indicated I could not be suffering from anxiety because I was 'not rocking' in my chair (this is a misunderstanding of how anxiety affects people). They said I 'made a meal' for myself each day, which is another inaccuracy among other inaccurate statements." Victoria

"The examination itself was ok but the report was appalling. It stated that I was 'well turned out with clean clothes'. I hadn't had a shower for a week and my jeans hadn't been washed in a month, needless to say I wasn't asked about that. I spent the whole time looking at the floor, but the assessor said I had normal eye contact furthermore the assessor spent the whole time typing so she couldn't possibly have observed that. She flatly contradicted what I said with no explanation or justification. I told her about all the things I couldn't do but she said I had no problem doing those things." Steven

Evidence review: accuracy of assessments

- In their 2018 inquiry into PIP (Personal Independence Payments) and ESA assessments, the Work and Pensions Committee identified inaccuracies in assessment reports as 'central' to a lack of trust in the process felt by many disabled people.⁵
- In the DWP's 2018 research into people's experience of the PIP process, participants reported that their decision letters and reports contained 'important inaccuracies regarding what was said during the assessment'.⁷
- The second independent review of PIP raised a range of issues with the decision-making process. It included concerns that the DWP's quality control processes focus too heavily on the technical quality of the assessment report and not on how faithfully it represented the assessment itself.⁸

- Ben Baumberg Geiger's research into the WCA for Demos involved focus groups with assessors who discussed placing significant weight on informal observations about a person's appearance and presentation.⁹
- A 2012 pilot found that of all benefits decisions overturned at appeal, 15% involved appeal judges making a different decision on 'substantially the same facts' that were available to the DWP. 41% of overturned decisions were made because of additional oral evidence that tribunal panels elicited through their questioning.¹⁰
- In a 2018 report by the Money and Mental Health Policy Institute, six in ten people with mental health problems making a claim for PIP or ESA felt that the assessor did not listen to them carefully.¹¹

Recommendation: The benefits system should be independently regulated



The case for an independent regulator

Every week hundreds of disabled people will go through an assessment for PIP, ESA or Universal Credit. The decisions which are made as a result of those assessments have a profound effect on people's lives. But there's evidence that many of those decisions are based on reports which are partial, misleading or inaccurate.

In recent years campaigners have called for assessments to be recorded and for people to be routinely given the reports from their assessments. Doth of these recommendations are intended to make assessments more transparent. In doing so they would change the behaviour of assessors and decision-makers, incentivising them to take more time and care with their reports. But we've also heard that the current methods of redress can make challenging inaccurate decisions a stressful and time-consuming process. That's true even when there's clear evidence that something has gone wrong.

Disabled people who want to challenge an unfair decision can pursue their case through the courts. It's a process that in some areas of the country takes longer than a year. There is no legal aid available for the vast majority of these cases and so people are required to represent themselves. For those who make it to tribunal the odds are on their side. At the time of writing, more than seven in ten decisions about disability benefits which reach this stage are overturned.¹³ However we know that many people are reluctant to challenge decisions which they believe are unfair. In 2017 we surveyed more than 800 people with experience of claiming PIP. Twenty-two percent did not believe their decision was fair but had no plans to challenge it, with many telling us they were too unwell to go through the process.

There is also an Independent Case Examiner who will investigate cases where people feel they have not been treated fairly. This is only after someone has exhausted the many levels of the Department for Work and Pensions' (DWP) complaints system. In the introduction to her most recent annual report, the current Independent Case

Examiner pointed to repeated failures to keep people who are in vulnerable circumstances safe, writing that 'too often this year I have seen cases where [safeguards] have not been followed'. She highlighted cases including an instance where someone with a mental health problem was forced to wait six years to challenge a decision, and another where someone who was homeless saw her benefits stopped for failing to attend an assessment for which she was given no notice.14 However the Independent Case Examiner has limited powers. They cannot proactively inspect the centres where assessments happen or where decisions about benefits take place. Their remit is focused on providing redress in cases where the system has failed, and on reporting about the trends their casework uncovers.

The lack of an independent regulator means that there is no organisation with the power and the resources to make sure that what is happening during assessments is consistent with the law, and that disabled people are treated with dignity and respect. Nearly every other major public service has a system of independent regulation, from Ofsted, to the Care Quality Commission. While no system of regulation is perfect, these bodies provide a level of oversight over public services which is currently missing from the benefits system.

The remit of a new regulator

A new regulator for the social security system would inspect the centres where assessments take place, as well as the centres where staff make decisions on benefits. They would review samples of the reports which assessors write. and the decisions made by the DWP as well as recordings of the assessments themselves. They would be independent from Government, with the power to compel evidence from the DWP and produce reports which hold them to account. They would monitor how well the Department 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 assessments for disability benefits.

Section 2: Giving people security

Emily experiences mental health problems including depression and anxiety. She also has a diagnosis of borderline personality disorder.

On the day of her Work Capability Assessment (WCA), she struggled to stay calm in the waiting room. She said that she began shaking uncontrollably and broke into tears. Her assessor was sympathetic, but she was still made to relive upsetting details about her illness and about her past experiences. She had to talk in detail about her suicidal thoughts and previous experiences of going into hospital for her mental health.

Emily told us the whole experience was demeaning and left her feeling worse for weeks. She didn't fault her assessor who was 'just following procedure' and who was visibly uncomfortable about the questions she was asking. But Emily was left feeling that the entire process was insensitive and unfit for purpose. She says she's now living with dread and fear at the prospect of having to go through a reassessment in the future.

The anxiety that face-to-face assessments can cause is well-documented. Following a legal challenge of the Work Capability Assessment, the High Court ruled in 2013 that the assessment process puts people with mental health problems at a substantial disadvantage. One of the most significant aspects of this ruling is that it did not just consider whether people with mental health problems were more likely to get incorrect outcomes, it also considered the impact of having to recount difficult and traumatic experiences. 15 The consequences of this can be stark. In a 2017 survey by Rethink Mental Illness, one in twenty participants said that the process of applying f or Personal Independence Payments (PIP) had contributed to an admission or readmission to hospital.16

What people with mental health problems told us about the impact of assessments

We heard from many people who found the stress of attending benefits assessments difficult or impossible to manage. This included people who struggle to leave the house and make journeys and to talk to people who are unfamiliar to them.

"I fight a battle every day with PTSD however I've been waiting over a year for therapy. My mood changes constantly, every minute is a battle with my thoughts and flashbacks and I'm just trying to keep myself busy to get through each day. I cried through the assessment, having to relive everything I'd put on the form and couldn't answer most things - it was traumatic." Becky

"For fear of being punished, I could not articulate to the assessor that I have visions that were tormenting me during the assessment interview and that, to appease my visions, in order to survive the moment, I must self-harm. I recall making excuses to use the toilet where I self-harmed and then returned to complete the assessment." Fabio

Some people told us that following distressing questions during their assessment they were preoccupied with suicidal thoughts, or that their mental health deteriorated in other ways.

"The worst bit is being asked to tell the assessor "Why haven't you killed yourself yet? What is stopping you from trying to kill yourself now?" I get asked that question at every assessment in those exact words, even at times when I was actively suicidal. All this does is make you question why exactly. When you are trying not to think about going through with it, the last thing you need is for a stranger to ask you to go into detail about it. It has pushed me closer to the edge in the past as I couldn't actually think of a reason not to do it!" Sarah

"The most difficult and stressful part of the PIP assessment was having to admit to having a history of suicidal thoughts and attempts. (Despite having already referred to this aspect in detail on the PIP form). To add insult to injury I was then asked to explain what was stopping me from succeeding with a suicide attempt! I cannot understand why they are allowed to ask such an impertinent and distressing question." Roger

We also heard from people who were asked direct and intrusive questions about self-harm, including people who were asked by their assessors to show self-harm scars.

"One assessor made me show the scars of my self-harm to see whether I had cut recently (which I had because of the stress of waiting for the assessment) and I felt so ashamed and embarrassed. I try to cover up my injuries, so few people know about what I do to myself. I felt awful that she didn't believe my doctors and my form and needed me to expose the scars." Shereen

Many of the people who told us about their distressing experiences were required to attend frequent face-to-face assessments, despite having long-term mental health problems which have

remained consistent across the course of their lives. Often, they had repeatedly provided medical evidence in support of their claim.

"I have bipolar disorder and chronic anxiety. This has affected me for many years. This is my third assessment in the last four years. All I can say is my mental health has deteriorated since these assessments started. I literally lived in fear of the letter arriving. I find the questions on the form utterly degrading and hate that I can't fit into those boxes. They also bring about a deep sense of shame about not working. I was always ambitious, actually studying for a degree in social work before I was diagnosed, as well as working and doing volunteering. I became so low with this most recent assessment that I was seriously considering suicide as a way out. I found it unbearable." Nadia

Evidence review: risks of frequent assessments

- In a 2013 ruling, the High Court upheld a
 decision by the Upper Tribunal which found
 that people with mental health problems were
 put at a substantial disadvantage by the Work
 Capability Assessment. One reason for this
 was the stress and anxiety the process causes
 for people with mental health problems.¹⁷
- A 2015 study published in the Journal of Epidemiology and Community Health looked at the association between the frequency of WCA reassessments and mental health outcomes in local authority areas across England. It found that each additional 10,000 people reassessed was associated with an additional six suicides, 2700 cases of reported mental health problems, and the prescribing of an additional 7020 antidepressants.¹⁸
- In 2019, The Money and Mental Health Policy Institute's research into PIP and ESA, found that nine in ten (93%) of survey participants saw their mental health deteriorated in anticipation of an assessment and 85% saw their mental health deteriorate afterwards.¹⁹
- In 2017, Rethink Mental Illness's survey of over 650 people with experience of mental health problems, 5% of participants said that the stress of applying for PIP contributed towards an admission or readmission to hospital.²⁰

- In his final independent review of the Work Capability Assessment, Paul Litchfield called for further investigation into short award periods, 'since rapid reassessment is stressful for individuals, burdensome for the DWP and expensive for the taxpayer'.²¹
- In the 2019 report 'State of Hunger' research for The Trussell Trust found an association between failed PIP assessments and foodbank use, with every 100 failed PIP assessments associated with an additional 93 food parcels distributed that year.²²
- A qualitative study of 50 disabled people's experiences commissioned by the Disability Benefits Consortium found that regardless of the outcome of assessments disabled people reported that that the process of applying for benefits damaged their self-worth, confidence and wellbeing.²³
- In The Activity Alliance's 2020 survey of more than a thousand disabled people, two in five (41%) said a fear of their benefits or financial assistance being taken away prevented them from trying to be more active. That rises to half (50%) of people with mental health problems.²⁴

Recommendation: Disabled people should have the right to apply for long-term awards



Many of the experiences we heard in writing this report would be plainly unacceptable in any system of benefits assessments. For example, no-one should be forced to recount details of trauma, self-harm or suicide attempts as part of the process of claiming benefits. And people who are required to attend assessments should never be asked to recount historic information that they have already provided in previous assessments. In the first chapter of this report we conclude that the benefits system needs an independent regulator. Making sure that disabled people can be confident that they'll have their rights upheld and that they'll be treated with dignity and respect when they apply for benefits should be part of the remit of that regulator.

In many cases the frequency of benefits assessments is making people more unwell. Many disabled people will have an impairment or condition which is likely to last for most or all their life. This is too rarely recognised within the benefits system. There are now processes within both PIP and the Work Capability Assessment to stop reassessing people with conditions which are lifelong and progressive. Yet these processes still give staff making decisions a significant amount of discretion, even when there is clear medical evidence about a person's prognosis.²⁵

The process also lacks transparency. Disabled people can't specifically apply for a long-term award and aren't told the criteria for receiving one. We regularly hear from people with

long-term mental health problems such as schizophrenia who are required to attend assessments every year or eighteen months.

This matters because without long-term security people who are disabled or unwell are denied the time and space they need to build up independent lives. Too many people with mental health problems tell us they live in fear of seeing their source of income removed, and this anxiety prevents them from doing the things they'd otherwise want to do, like see friends and family, become more physically active, study or volunteer.

How to build security back into the system

The UK Government must end the current system of frequent face-to-face reassessments, which we know is causing avoidable harm. They could achieve this in practice by giving disabled people a way to apply for a long-term benefit award when they first make a claim. This should include creating transparent criteria for long-term awards, which disabled people could use to appeal their decisions should they need to. These criteria should give weight to medical evidence but also to a person's own history and the way in which their impairment has developed so far. Decisions about the length of a person's award should also consider the likely impact of frequent assessments on their health and wellbeing.

Section 3: Giving people choice

Roisin was in a difficult situation even before the coronavirus pandemic hit the UK. After being in stable work for most of her life, she had reached a point where her anxiety and depression were making it impossible to continue. After spending time in hospital recovering from a mental health crisis, she was still experiencing regular periods of disassociation which disrupted her daily life. She had known for some time that things needed to change but she also felt ashamed about the prospect of claiming benefits. In March, Roisin took the plunge, stepping down from running a successful business and putting in an application for Universal Credit.

Her experiences could not have been more different from one another.

Roisin's application to Universal Credit went smoothly. Her Work Coach saw that she had a note from her GP and told her over the phone that she should take returning to work at her own pace — she wouldn't be forced to do anything before she was ready. Her Work Coach also said that Roisin could be entitled to a higher award because of her health conditions and helped get that process going. Roisin had access to a lot of medical evidence about her mental health problems, and after sending off the forms was told that she had been successful.

When Roisin applied for PIP things went differently. Because of the coronavirus pandemic she was required to take part in an assessment over the phone. Before the assessment Roisin had asked if her psychiatrist could speak to the DWP instead, or if they would let him write to provide any extra evidence they needed. Her assessment provider told her neither would be possible. During the assessment itself Roisin struggled to cope, especially when her assessor asked her detailed auestions about suicidal thoughts. She felt that her assessor might have been more understanding if they could see how distressed she was becoming either face-to-face or through a video call. Roisin scored zero points on her assessment and is dreading the process of going through a lengthy appeal.

The coronavirus pandemic has changed the experiences of applying for benefits for many people like Roisin. Some people have found things

easier. We have heard from people who struggle to use public transport or be out in public and who have found assessments over the phone a real improvement. Others like Roisin have struggled to cope with assessments over the phone, and have found the system too inflexible about how the DWP gets the information it needs.

What people with mental health problems have told us about remote assessments

Some of the people we spoke with said they preferred being able to have an assessment over the phone and being able to avoid stressful and anxiety-inducing journeys.

"A face-to-face assessments would be a struggle With the public transport, I feel anxious to do that on my own. Even if I was with someone just traveling on public transport. I would be really be scared." Sam

Others told us that they struggled to cope with taking part in assessments over the phone.

"It was just basically like a quickfire question round. I don't recall much of the conversation because it hit a lot of big triggers and so I think a lot of it blocked. She said, "Can you tell me what your triggers are please?" I can't sit there on the phone to a stranger that I don't know and answer that. Then she just said, "Have you ever felt suicidal?" I just thought you haven't read my notes - because then you'd see how many times I've tried, so I just sat there. She said, "Have you tried?" I said, "yes," it was as quick as that. "Have you ever been suicidal?" "Yes." "Have you ever tried?" "Yes." "Do you feel suicidal now?"" Roisin

"Some people straight away said I don't like the idea of a phone call, can't do that on my own. At least three of my clients I've assisted live alone. I think the thought of just being in that situation which was completely alien to them, being on their own, without anyone there just to reassure them, give them that nod or glance, would have been too much." Local Mind adviser

Even when people were happy to talk over the phone, there were many cases where they did not receive the adjustments they needed. In some instances people had their appointments rescheduled at short notice, in others they were not able to have someone else on the call with them for support.

"She just called me in the morning and I was working and it went to voicemail because I was at work. Then I listened to the voicemail. She was like, "Oh, we've got an assessment today, and I'll call back at this time so we can plan when we want to do it." I burst into tears. I was just overwhelmed immediately because I was already at work and I was not having a great day with my health. Exactly the kind of thing that really spikes my anxiety is just a sudden appointment. I thought, "I can't deal with this. I need to prepare. I don't even know what's going to happen."" Nadia

And for those who could not cope over the phone, it was difficult to secure a different way of being assessed.

"With current issues around the phone assessments, we've had problems with getting the PIP assessment centre to accept that some

people will not be able to take part in a phone assessment. It seems very dependent on who you get to speak to as to whether they will make it difficult or not. I have had to call the DWP and get them to make it clear that the assessment centre needs to understand this and make as much effort as possible to gather information from other people who know the claimant and do a paper based assessment instead, but I've struggled to find clear written guidance on this from them." Local Mind adviser

Several people we spoke with said that they would prefer the option of taking part in a video call in order to get more visual cues from assessors. However others said that they would struggle to use video conferencing software or didn't have internet access in their homes.

"Having options like video, over the phone or face-to-face, you're at least helping people to choose what is going to not just exhaust them immediately or overwhelm them immediately, right? It becomes less intimidating because you're able to choose. A process like this doesn't have to be so horrible. Having those options would be a massive help for so many people I think" Nadia

Evidence review: remote assessments

- In 2018 the Money and Mental Health
 Policy Institute published research which
 found that 54% of people with mental health
 problems have serious difficulties using the
 phone to carry out essential admin. This
 compares to 32% of people without mental
 health problems.²⁶
- Research published by the Department for Work and Pensions in 2020 found that one in five people claiming PIP do not have internet access at home. This rises to one in four people claiming ESA.²⁷
- In 2020 the Benefits and Work forum carried out a survey with more than 250 of their members who had experienced a PIP telephone assessment. People reported mixed experience of their assessments. The majority of respondents did not have technical problems with their call and felt their assessor's manner was either neutral or positive. Some of the most common problems were respondents saying that assessors had not read their forms and had not asked enough relevant questions. The survey also highlights cases where people who struggle to engage over the phone were not offered any alternative ways to complete the application process.²⁸

Recommendation: Disabled people should be able to choose the format of their assessment



Mental health problems affect people differently. You are being set up to fail if attending a face-to-face assessment means risking a panic attack on a crowded bus or train. But the same is true of being required to talk over the phone if your anxiety makes that impossible. Or needing to take part in a video call when you can't access the internet at home. Or being given an appointment time which means you can't get the support you need from friends and family.

When we spoke to people about their experiences of claiming benefits during the pandemic, overwhelmingly people told us they wanted choice and flexibility. People wanted

the option of speaking by phone, by video call, and when safe to do so face-to-face. People also wanted the system to make it easier to put across their case in other ways, for example by giving them option to send in additional information by text or email. Or for the DWP to speak directly to an adviser or health professional on their behalf.

For the people we spoke with, the prospect of having these options was not just a question of making their experience better. For some it was about having the basic opportunity to participate in the assessment process, to put their case across, and to have a fair hearing.

Section 4: Asking the right questions

Victoria has experienced depression and anxiety for over forty years. As a teenager she developed anorexia and bulimia which have affected her for large parts of her life. Over the past few years she has been in and out of hospital for her mental health and has at times been under the care of her community mental health team. Victoria is now discharged but she says she is still struggling with her health and feels very isolated. She hasn't worked for many years although she hopes to return to work if she can get the right support.

When Victoria last went for a Work Capability Assessment (WCA) in 2017, she sought help from Citizens Advice and sent off a bundle of evidence including letters from her GP and her community mental health team. She did her best to describe how her mental health affected her on the form, but she still felt like the questions were mostly asking her about physical health problems.

The face-to-face assessment felt similar. Victoria said the assessor seemed to be putting standard questions to her and that none of them seemed to fit her situation. Whenever Victoria tried to explain how her mental health affected her, she was told to return to the questions she was being asked. She said it felt like the assessor was trying to finish the process guickly and that she didn't have space to say what she needed to. She was even asked to perform physical tasks like stretching, even though she wasn't claiming Employment and Support Allowance (ESA) because of a physical impairment. Victoria told us her experience of her assessment left her feeling angry and humiliated and like she was being put on trial rather than listened to.

When the Department for Work and Pensions conducted in its own research about disabled people's experiences of Personal Independence Payments (PIP), it found that others had been through a similar experience to Victoria. Its report found that people with mental health problems, 'spoke of feeling that the face-to-face assessment had been overly focused on physical conditions and had not touched on the key reasons they were claiming PIP.'29

What people with mental health problems told us about the structure of assessments

We heard from people who told us that they struggled to articulate how their mental health affected them on forms and during face-to-face assessments.

"My assessment was delayed by two hours which exacerbated my anxiety to the point where I was shaking and struggling to get my words out. The assessor was very direct with his questions and on occasions I struggled to articulate myself both clearly and calmly." Peter

"During my assessment I spoke so quickly that I was stumbling on my words and even forgetting words or how to pronounce them, I couldn't sit still and kept glancing at the door." Ellen

Some people told us that they found it difficult to fit their experiences into the structure of their assessment but that it was hard to get this across or that their assessor did not allow them to express things in their own words.

"I have been treated for depression and anxiety since the age of fifteen years, I am now 56. The interview consisted of the assessor sitting at a computer, putting the standard questions to me, and ticking the boxes. None of the questions seemed to fit my situation. She seemed only to want to complete the process as quickly as possible. She was not interested in anything I wanted to tell to really describe how my illness affected my ability to perform daily activities. She seemed to nod frequently and be prompting only positive responses from me, which would create an inaccurate picture of my situation and skew it towards being able to do everything and be fit for work." Victoria

"You could go into great detail (and I'm sure we all do) about our symptoms and how they affect our day to day lives but unless it is vocalised in a particular way, using their language, you won't score any points." Anne

For many people this was made harder by a feeling that they needed to complete the assessment quickly, or to prove short or straightforward answers to the questions they were being asked.

"The lady who interviewed me refused to listen to the difficulties that my mental causes me. She kept saying 'let's just stick to the questions'. It was extremely distressing I became very anxious because every time I tried to stand my ground, she repeated that she didn't like my tone!" Kenneth

"Unlike the last WCA I had, the assessor this time was much better and nicer. However, she didn't give me time to finish my answers and although she reassured me that she understood what I was trying to say, I was worried that I had not been able to explain the scale of the difficulties I faced." Marcus

The criteria for both PIP and the WCA include references to how a person's condition varies and fluctuates. But we heard from many people who were not asked questions about this during their assessment or who were not given room to explain exactly how their health fluctuates.

"It's exceptionally difficult to answer the questions as my symptoms can vary from day-to-day, and as such each question has to be noted as "it varies". I'm required to fill out a symptom diary or be faced with a barrage of questions in a face to face interview as to how often I'm affected. Time after time I try to explain how unpredictable the nature of my illness is - yet the assessor is insistent on having a set frequency." Liv

Some people told us that they found the criteria and the types of questions they were asked abstract and removed from their real experiences. This was particularly true of the Work Capability Assessment, which does not ask questions about people's previous experiences of working or looking for work.

"The questions were focused on quantitative analysis again. Like how many times do you leave the house each week? Rather than how difficult is it to do so. Any mention of how my illness has affected previous jobs was dismissed as not being part of the assessment which is clearly ridiculous."

Examples of experiences which were not taken into account included people who talked about how their ability to work fluctuates significantly when they are unwell, people who struggle to get the adjustments they need from employers, and people who described only being able to work in specific kinds of roles.

"I had a lot of issues in the last couple of years with time keeping. I take medication for bipolar, and I'm often drowsy in the mornings, and I was late for work a lot. I wasn't offered flexible working or allowed to come in later, even though it wouldn't have affected my work." Michael

"I have bipolar so my mood swings change day to day. Extreme fatigue & low energy due to poor sleep affects my concentration and memory, hypomanic days means I do far too much in too little time. I have to navigate the fluctuating levels and work flexibly around my mental health – which is exhausting, in and of itself. I lost my previous job in an arts organisation due to my poor mental health. I now work less than sixteen hours a week part-time as a care assistant with occasional freelance work." Patrick

There were also areas where the Work Capability Assessment asked relevant questions but assessed the answers in a restrictive and narrow way. For example people were asked if they are able to 'cope with social engagement', but the questions did not distinguish between the kind of social engagement that's involved in going to the shops or seeing a GP, and what's required to work with customers and co-workers in real workplaces.

"I have anxiety, depression and body dysmorphia. On my most severe days, I am unable to work. It's harder as I work in customer services/ interacting roles. I have had panic attacks in the past and it affects how I relate to my colleagues as some days I can't look people in the eyes. Some days, I can't hold in everything and I cry on my way home from the bus-stop." Kathryn

"I can work, but I cannot cope with the stress of people. In my last job I was asked to attend meetings and I became so stressed that my weight went down to under eight stones. I could not eat properly and I am still struggling to put on weight. I do not go out except to the chemist if my mother needs help. Otherwise I am just at home. However, I can appear very in control when I need to and that is why the person at the assessment said I was ok to work." Chris

Evidence review: assessment criteria and structure

- In his 2018 report for Demos, Ben Baumberg Geiger highlighted limitations in the design of the WCA, particularly for people with multiple conditions. He argues 'each impairment needs to be quite severe before it receives any points under the WCA, so disabled people with many different types of lower-level impairments that in combination severely reduce their work capability – particularly because of pain and fatigue may even score zero points at the WCA.'30
- In a 2012 evaluation of decision-making for the WCA, DWP decision-makers reported feeling that 'the design of the assessment process did not allow for the accurate measurement of the manifestation and severity' of mental health problems. Some decision-makers also reported that they felt assessors were likely to underscore people with mental health problems as they 'did not treat mental health conditions to be credible'.³¹
- In Paul Litchfield's final review of the WCA he considered the findings from an 'Evidence-Based Review' into the assessment process.

- He concluded that 'a semi-structured interview format may improve people's perception that they have had a better opportunity to discuss their capability and help to build better rapport with the [assessor]'32
- The DWP's research into experiences of PIP found that many people with mental health problems felt that the forms and assessment conversations did not give them the space to talk adequately about how their condition affects them or to describe how their health fluctuates. The report also said that 'this group spoke of feeling that the face-to-face assessment had been overly focused on physical conditions and had not touched on the key reasons they were claiming PIP.'33
- In its 2019 research, The Money and Mental Health Policy Institute found that fewer than one in four people with mental health problems felt they were able to explain how their mental health affected them during their assessment.³⁴

Recommendation: Disabled people and independent experts should help decide the questions for benefits assessments.



Why the criteria for disability benefits need reform

When both PIP and the Work Capability Assessment were introduced, they were described as 'functional assessments'. Successive governments said these assessments intended to look at the impact of a person's impairment on their life and not just what condition they have. But we know from people with mental health problems' first-hand experiences that both assessments are failing to achieve that goal and they're failing in very similar ways.

The Work Capability Assessment is intended to be an assessment of whether someone can work. However it asks abstract questions about a person's ability to carry out activities which often have no clear link to the real world of work. You might, in the language of the DWP, be found able to 'cope with social engagement' if you can travel to your local shop and buy a pint of milk from someone you know well who works there. That doesn't mean you could cope with meeting new people every few minutes while working in a busy supermarket or bar. It doesn't mean you could cope with an angry customer or frustrated co-worker. And it doesn't mean you could do these things week in week out, without suffering setbacks which take you away from work for days or weeks at a time.

Similarly, the PIP assessment is intended to work out whether you are likely to experience extra costs as a disabled person. But it follows the same abstract model as the Work Capability Assessment. For example it doesn't recognise the costs associated with needing

someone to stay with you overnight to keep you safe, or the costs you incur if you struggle to open your post or make phone calls as a result of a mental health problem.

A process that puts disabled people in control

The current assessments aren't working in part because they're based on criteria which don't capture the reality of disabled people's lives. The solution needs to be building something new which uses disabled people's experiences as a starting point. We want to see the UK Government create a new independent commission to come up with detailed proposals for reform. That commission would involve disabled people with experience of claiming benefits in its leadership and consult widely with disabled people to inform its reports to Government. It would include other experts including carers, GPs, mental health professionals, welfare rights advisers, and occupational health practitioners. It would be tasked with proposing new kinds of questions and criteria for both the WCA and PIP which better reflect how a person's impairment can affect their chances of finding sustained employment, and the extra costs they incur in their daily lives.

Section 5: Taking the fear out of the system

Rebecca first started experiencing mental health problems while working in events. She began struggling to cope with leaving the house and started taking periods of sick leave. Eventually she lost her job. With no money coming in and a month's worth of childcare bills left to pay, she made a claim to Universal Credit, not knowing what to expect.

Rebecca was required to spend thirty-five hours a week searching for work, at a time when she was still experiencing panic attacks whenever she went out in public. She said that she felt unable to cope with appointments in a busy and noisy open plan office and that she didn't know how she would have kept going without help from her crisis team and her support worker.

One of the things Rebecca found most frustrating about her experience is that she wanted to be well enough to return to work. She initially thought that she might get some of the support that she needed from her Jobcentre, but she ended up struggling so much that a family member stepped in and became her appointee so that she no longer needed to manage her interactions with the DWP. She has since been through a Work Capability Assessment (WCA) and no longer is required to search for work. Rebecca told us she now has the security to focus on her hopes for recovery and on returning to work at her own pace.

What people with mental health problems told us about requirements to find work

We heard from many people who told us that Jobcentre appointments were a significant source of distress and anxiety. People told us that the fear of benefit sanctions could become overwhelming and at times become a driving factor leading them to experience a mental health crisis.

"I stopped spending money on food and heating to save for an uncertain future, and relapsed terribly with anorexia. I had to give up my voluntary work and go into hospital as I was physically and mentally very unwell. The admission lasted a year - costing hundreds of thousands of pounds which I feel terribly

guilty about. But if I had felt more supported to take recovery at my own pace, and not feared financial repercussions and sanctioning, then I do not think (nor do my medical team) that I would have relapsed at that point." Louisa

Many people told us that they wanted to work or to take other steps that would allow them to live more independently. The fear of sanctions made it far harder for them to do this. It also made Jobcentres feel like threatening or unwelcoming environments, even when they felt staff were trying their best to be understanding or empathetic.

"For a week before each appointment I struggled to sleep and eat, I had panic attacks- sometimes several a day. I just could not face the thought of the DWP because of the power they had over my life. This stress led to me considering self-harm and suicide, which I had previously attempted and been hospitalised for." Marcus

People claiming Universal Credit can have their requirements to search for work tailored or reduced. However, many of the people we heard from struggled to communicate their need to have their work requirements reduced, or to convince Jobcentre staff to do so.

"I did not get a chance to talk about mental health, but I did about physical. At the time my requirements were being discussed I was dissociating far too hard to be in any state to have a conversation about them, and so they ended up just being a list of things the Work Coach thought were good that I hadn't discussed or really understood properly." Dan

"When we did the commitment, it felt like I was being spoken to like a child, I didn't really have chance to say much about any of it other than being asked to agree. There were no questions asked about any health or mental health conditions." Zahir

Evidence review: requirements to look for work

- The National Audit Office found that receiving an Employment and Support Allowance (ESA) sanction led to disabled people spending less time in work and more time receiving benefits.³⁵
- Evaluation of a set of Jobcentre trials in 2015 found that Jobcentre staff were concerned that they could not adequately judge whether work requirements were appropriate for people who are very unwell. The report said that "at the extreme, some claimants presented themselves as being suicidal and Work Coaches had to handle such cases with particular care. Some Work Coaches raised concerns that it could be difficult for them to judge how claimants are affected by their health conditions, particularly in relation to mental health." 36
- The Social Security Committee's 2019 research into the effectiveness of claimant commitments in Universal Credit found 'a lack of consistency in the approach to tailoring of claimant commitments and a range of issues that could lead to significant detriment, particularly to claimants in vulnerable circumstances'.³⁷
- Analysis of the 'More Intensive Support' trial in 2015 found that people with mental health problems spent less time in work and more time receiving benefits following an increase in the intensity of work requirements.³⁸
- The DWP's evaluation of a pilot aimed at supporting people with health conditions into work found that participants valued the support being voluntary because it gave them a greater sense of control when compared to previous support they had been offered from Jobcentres.³⁹

- Polling conducted for Demos found that only one in four people with mental health problems would trust Jobcentre staff to treat them fairly.⁴⁹
- The DWP's evaluation of a pilot giving people more opportunities to challenge sanctions found that people with mental health problems were particularly unlikely to challenge a sanction even if they thought it was unfair. The reasons for this included people feeling too afraid to contact the DWP or believing that their challenge would never succeed.⁴¹
- In 2018 a longitudinal study tracking fifty-eight disabled people's experience of conditionality over three years, found that conditionality 'did very little to move disabled people closer to the labour market' but instead pushed disabled people further away from work. The same study also concluded that routinely 'conditionality also had a negative effect on respondents' health and undermined their wider social inclusion.'42
- Research from The Behavioural Insights
 Team points to the impact of time-scarcity
 and financial scarcity on our ability to
 make decisions, suggesting that requirements
 to look for work 'may in theory worsen
 a person's attention, self-control, and
 long-term planning'. The report calls for
 the DWP to conduct further research into
 the issue, saying 'the individual costs of
 depleting a person's psychological resources
 may be greater than the financial benefits
 the system provides'.⁴³

Recommendation: Employment support should be voluntary for disabled people



Benefit sanctions don't work for disabled people and people who are unwell. Research from the National Audit Office and from the Department for Work and Pensions (DWP) itself have found repeatedly that sanctions lead to people with health conditions spending less time in work, not more.44 Sanctions also cause fear. Many people with mental health problems find the fear of being threatened with a sanction overwhelming. It colours every interaction they have with the Jobcentre, making them scared to engage and mistrustful of the staff who hold that power. But with the move to Universal Credit more and more disabled people are subject to sanctions, including people who are waiting to be sent for a Work Capability Assessment, and who may later be found to be too unwell to work.⁴⁵ In the worst cases the pressure is leading people into crisis and putting them at serious risk of harm.

Removing sanctions is also a necessary part of making Jobcentres services that can meet the needs of the people who use them. We know that for people to be helped back to work, they need to be able to trust the person helping them. That's especially true for people with mental health problems, where the process of finding a job can involve experimentation and risk. Currently the high volume of mandatory appointments is a barrier to Jobcentre staff spending time building trust and goodwill with the people they support. 45 Making employment support voluntary would be the first step towards changing that.

Removing sanctions in practice

In Chapter 3 we recommend that the Government establish an independent commission to look at options for reforming disability benefits assessments. One task for this commission could be to review how a reformed WCA could make sure that no disabled people are subject to the threat of sanctions.

However, there are also immediate reforms the UK Government could make to end sanctions for disabled people within the current system. Currently, anyone who applies for Universal Credit can face the threat of sanctions according to the discretion of Jobcentre staff. This includes many disabled people and people with health conditions who may later be assessed and found not fit for work. It also includes people who have had their barriers to work recognised through the Work Capability Assessment but who have been required to carry out work preparation activities. We want to see the Government remove work requirements for these groups so that no-one faces the possibility of seeing their income cut if they are too unwell to do what they are asked.

Conclusion and next steps

The five solutions in this report do not represent a comprehensive roadmap for fixing all the problems of the benefits system. Instead they are an important first step towards building a more compassionate approach to disability benefits.

- An independent regulator for the benefits system would redress the imbalance of power which leaves many of the people we support struggling to challenge inaccurate decisions.
- 2. A clearer route to long-term awards would reduce the burden of repeated assessments on people who are already unwell.
- 3. Giving people more choice over their method of assessment would help make sure that all disabled people have the opportunity to put their case across and get a fair hearing.
- 4. An independent commission led by disabled people would be a powerful commitment to working with people who have experience of the system to design the future of disability benefits assessments.
- 5. An end to benefit sanctions for disabled people would give people who are unable to work the financial security and peace of mind needed to stay well and move forward with their lives.

All of us should be able to turn to a benefits system that's there when we need it. We should know that we'll get a fair hearing, that we'll be listened to and taken seriously. And benefits should give us the security we need to focus on moving forward with our lives. Politicians and policymakers need to show leadership in building a benefits system which respects the rights of people claiming benefits, and which treats everyone who needs support with compassion, dignity and respect.

End notes

- In 2016/17 there were 418,980 claims to ESA and 276,493 claims to PIP from people who reported a mental health condition as their primary condition. Data accessed via DWP Stat Xplore [08/11/2019].
- 2. The survey, of over 1,500 people who had used mental health services in the previous two years, found that of those who had considered or attempted suicide 29 per cent cited the fear of losing, or the loss of welfare benefits. See Mind, 2016. 'One in two people with mental health problems have felt suicidal because of money, housing or benefits issues'.
- 3. Work and Pensions Committee, 2018a. PIP and ESA assessments, House of Commons.
- The proportion of decisions overturned at tribunal was 75% for both ESA and PIP. See: Ministry of Justice, 2019. Tribunal Statistics Quarterly, April to June 2019
- Department for Work and Pensions, 2012.
 Social Security and Child Support Tribunal hearings: Early analysis of appeals allowed from pilot data
- 6. Work and Pensions Committee, 2018a. PIP and ESA assessments, House of Commons.
- Department for Work and Pensions, 2018.
 Personal Independence Payment Claimant Research - Final Report
- 8. Gray, P., 2017. The Second Independent Review of the Personal Independence Payment Assessment
- 9. Geiger, B. B., 2018. A better WCA is possible, s.l.: Demos.
- 10. Department for Work and Pensions (2012)
- 11. Six in ten participants (60%) felt that the assessor did not listen to them carefully. Base for this question: 260 people who have undergone a medical assessment in the last two years. See: Money and Mental Health Policy Institute, 2019. The benefits assault course
- 12. Work and Pensions Committee (2018a)
- 13. Ministry of Justice (2019)

- Independent Case Examiner, 2019. DWP complaints: Annual report by the Independent Case Examiner 2018 to 2019,
- 15. The ruling in the Upper Tribunal identified more than twenty difficulties people with mental health problems experience in the WCA process including 'finding the process itself intimidating and stressful, and, in some cases that having a long-lasting negative effect on their condition. This conclusion was upheld in a subsequent ruling by the Court of Appeal. See MM & DM v SSWP [2013] UKUT 0259 (AAC).
- 16. Based on a survey of over 650 people with experience of mental health problems. See Rethink Mental Illness, 2017. It's broken her,
- 17. MM & DM v SSWP [2013]
- 18. Barr, B. et al., 2016. 'First, do no harm': are disabiltiy assessments associated with adverse trends in mental health? A longitudinal ecological study. Journal of Epidemiology & Community Health, pp. 339-345.
- Base for this question: 259 people who have experienced a medical assessment in the last two years. See Money and Mental Health Policy Institute (2019)
- 20. Rethink Mental Illness (2017)
- Litchfield, P., 2014. An Independent Review of the Work Capability Assessment - year five, s.l.: s.n.
- 22. Based on longitudinal modelling using a panel dataset of 325 local authorities observed over eight years. See The Trussell Trust, 2019. State of Hunger and accompanying technical report.
- 23. Disability Benefits Consortium, 2019. Has welfare become unfair?
- 24. Based on a survey of over 1000 disabled people. See Activity Alliance, 2020. Annual Disability and Activity Survey

- 25. For details about what these processes involve see: House of Commons Library., 2019. Briefing paper: ESA and PIP reassessments
- 26. Online survey of 2,078 people, carried out by Populus 11-13 May 2018. Data is weighted to be nationally representative. See: Money and Mental Health Policy Institute, 2018. Access Essentials
- 27. Department for Work and Pensions, 2020.

 DWP claimant service and experience survey
 2018 to 2019
- 28. Interim finds from a survey of over 250 people with experience of PIP telephone assessments. See: Benefits and Work, 2020. What PIP telephone assessments are really like, part two
- 29. Department for Work and Pensions (2018)
- 30. Geiger, B. B. (2018)
- 31. Department for Work and Pensions, 2012.

 Decision making on Employment and Support Allowance claims.
- 32. Litchfield, P., (2014)
- 33. Department for Work and Pensions (2018)
- 34. Fewer than a quarter of participants (23%) felt able to explain how their mental health problems affected them in the assessment, and fewer than one in five (18%) felt their assessor understood the impact of their mental health problems. Base for this question: 266 people who have undergone a medical assessment in the last two years. See: Money and Mental Health Policy Institute, (2019)
- 35. The study found 'for Employment and Support Allowance claimants we found sanctions had less effect. However, sanctions reduced claimants' time in employment, particularly part-time employment. Most of the reduction meant people spent more time claiming, suggesting sanctions may have discouraged some claimants from working'. See National Audit Office, 2016. Benefit sanctions,
- 36. Department for Work and Pensions, 2017. The 2015 ESA Trials: A synthesis,
- 37. Social Security Advisory Committee, 2019.

 The effectiveness of the claimant commitment
- 38. Geiger, B. B., 2018. Sanctioning disabled claimants: interrogating the evidence. [Online]

- 39. Department for Work and Pensions, 2018. Evaluation of the Personalisation Pathfinder Trial.
- 40. Demos commissioned Opinium Research to carry out a representative survey of 2,000 UK adults. See Glover, B., 2019. Pathways from Poverty: The future of the DWP,
- 41. The evaluation of the 'yellow card' trial for benefit sanction warnings was published in correspondence as part of the Work and Pensions Committee's inquiry into benefit sanctions. See: Work and Pensions Committee, 2018b. Letter from Minister for Employment to Frank Field regarding Benefit Sanctions data,
- 42. Dwyer, P. et al., 2018. Final findings: Disabled people, s.l.: Welfare Conditionality.
- 43. The Behavioural Insights Team, 2016. Poverty and decision-making, s.l.: s.n.
- 44. National Audit Office (2016)
- 45. Work and Pensions Committee, 2018c. Benefit Sanctions, s.l.: House of Commons.
- 46. For analysis of the issues surrounding trust, conditionality and Jobcentres, see: Pollard, T., 2018. Pathways from Poverty: A case for institutional reform, s.l.: Demos.

People, Not Tick-Boxes 25

