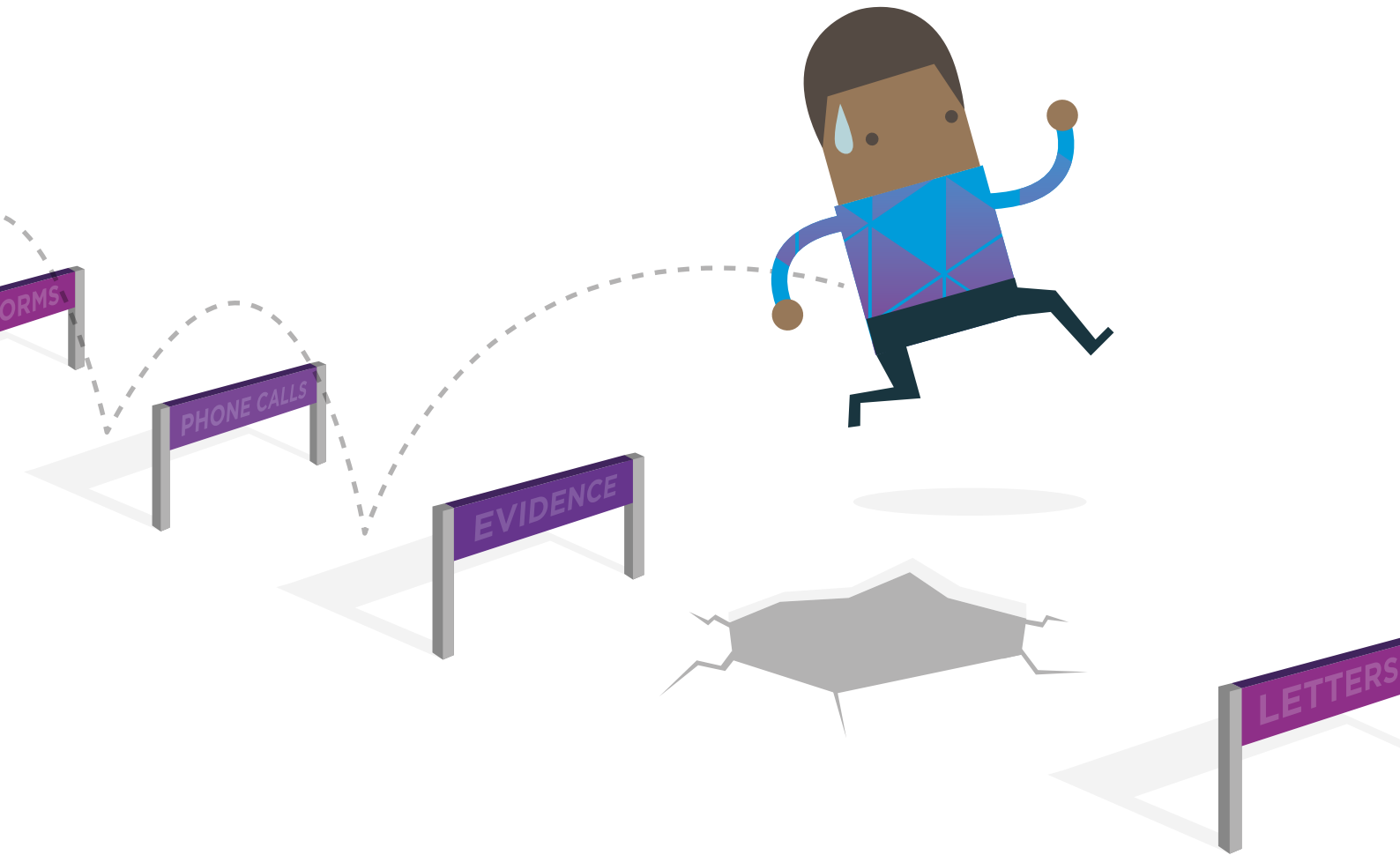




MONEY AND  
MENTAL HEALTH  
POLICY INSTITUTE



# THE BENEFITS ASSAULT COURSE

---

Making the UK benefits system more accessible  
for people with mental health problems

Nikki Bond, Rachel Braverman and Katie Evans

# Contents

<b>Executive summary</b>	<b>5</b>
<b>Introduction</b>	<b>8</b>
This report	10
<b>Section one: The context and the challenge</b>	<b>13</b>
1.1 The problems faced by people experiencing mental health problems	14
1.2 Why are people experiencing mental health problems struggling to access benefits?	16
1.3 Mapping the pain points	17
<b>Section two: Initial application</b>	<b>19</b>
2.1 Complex and demanding administrative processes	19
2.2 Inaccessible communication channels	20
<b>Section three: Providing information and evidence</b>	<b>23</b>
3.1 Complex and demanding administrative processes	23
3.2 Relationship dynamics	23
<b>Section four: Assessments</b>	<b>26</b>
4.1 Inaccessible appointments	27
4.2 Relationship dynamics	27
<b>Section five: Ongoing management</b>	<b>30</b>
5.1 Complex and demanding administrative processes	30
<b>Section six: Challenging decisions</b>	<b>34</b>
6.1 Complex and demanding administrative processes	34
6.2 Relationship dynamics	36
<b>Section seven: Conclusion and recommendations</b>	<b>38</b>
7.1 Universal Design amendments	38
7.2 Acute mental illness	40

## Publication

The Money and Mental Health Policy Institute,  
March 2019

22 Kingsway, London, WC2B 6LE

© Money and Mental Health Policy Institute, 2019

The moral right of the authors has been asserted. All rights reserved. Without limiting the rights under copyright reserved above, no part of this publication may be reproduced, stored or introduced in a retrieval system, or transmitted, in any form or by any means (electronic, mechanical, photocopying, recording or otherwise), without the prior written permission of both the copyright owner and the publisher of this report.

This report represents the research and views solely of the authors and of the Money and Mental Health Policy Institute.

## Acknowledgements

The Money and Mental Health Team would like to express our gratitude and admiration to all those members of our Research Community who gave up their time and shared their experiences.

Thank you to Ayaz Manji, Chilli Reid, Gwennan Hardy, Lee Healey, Jamie Thunder, Josie Tucker, Chloe Wright and Billy Boland for their advice and support of the project. All views remain those of the authors, as are any mistakes.

A special thanks to the rest of the team at Money and Mental Health, in particular to Helen Undy and Brian Semple for excellent editorial support, and Merlyn Holkar for assistance checking statistics.

## About the authors

Nikki Bond works as a Research Officer at Money and Mental Health. Nikki's background is in financial services where she worked supporting people with mental health problems to manage their finances. Prior to this she worked in social care advocating for disadvantaged and marginalised groups.

Rachel Braverman is a Research Officer at Money and Mental Health. She holds a Master's degree in Public and Social Administration and has lived experience of mental health issues, both as a carer and an 'expert by experience'. Her background is in the voluntary advice sector, where she worked for two decades as a money adviser, manager, CEO and consultant.

Katie Evans is Head of Research and Policy at Money and Mental Health, where she leads a groundbreaking research programme exploring the links between mental health problems and financial difficulty. She previously worked as an economist and holds degrees from the University of Oxford and the London School of Economics.



## Executive summary

### **Many people claiming benefits are experiencing mental health problems**

- The Adult Psychiatric Morbidity Survey, the largest survey of the mental health of the English population, shows nearly half (47%) of working age adults receiving an out-of-work benefit have a common mental disorder, such as depression or anxiety.
- Two thirds of people claiming Employment and Support Allowance have a common mental disorder, and 43% will have attempted suicide at some point in their lives, compared to just 7% of people not claiming ESA.<sup>1</sup>
- Levels of undiagnosed mental illness are high, meaning some people claiming due to unemployment, low income or a physical health problem may also be experiencing a mental health problem, but be unaware of it. In other cases, people may not feel comfortable telling benefits agencies about their mental health problems.

### **Mental health problems can make navigating the benefits system harder, with serious consequences**

- Common symptoms of mental health problems include reduced concentration, increased impulsivity, memory problems and reduced planning and problem solving skills, all of which can make it harder to claim and manage benefits.
- Over 90% of recent claimants with mental health problems who responded to a survey of Money and Mental Health's Research Community reported some level of social anxiety when engaging with the benefits system. People report physical symptoms like a racing heart or sweating, and behavioural changes like avoiding dealing with benefits or using alcohol to cope.

- When people experiencing mental health problems can't access benefits alone, mental health practitioners spend clinical time supporting them. Problems with the benefits system drive increased demand for third sector services, including advice and food banks.
- The paused rollout of Universal Credit, and proposed pilot of Managed Migration, offer an opportunity to make the system more accessible.

### **Problems affect all parts of the claiming process, from initial applications through providing evidence and attending assessments, to managing payments and challenging decisions**

In a survey of 455 people with mental health problems who claimed Universal Credit, Housing Benefit, Employment Support Allowance, JobSeeker's Allowance, Council Tax Reduction or Personal Independence Payment in the last two years:

- Nearly all participants reported finding application forms difficult
- Four in five (82%) participants had difficulty finding the right information to send
- Nine in ten participants (93%) said their mental health deteriorated in anticipation of a medical assessment
- Over two thirds of participants said they always or often need help to attend appointments and assessments
- Four in five (81%) said they had been unhappy with a benefits decision, but many did not feel able to challenge the system.

1. McManus S et al (eds.) Mental health and wellbeing in England: Adult Psychiatric Morbidity Survey 2014. NHS Digital. 2016.

## Improving access to benefits for people experiencing mental health problems

A combination of high levels of undiagnosed mental illness and stigma means efforts to improve access to the benefits system for people experiencing mental health problems that either focus on those who are claiming because of a mental health problem, or rely on disclosure, will never completely address the problem. Instead, the government must take a universal design approach – assuming any claimant could be affected by a mental health problem, and creating systems that a person experiencing common symptoms would not struggle to access. Specific adjustments could include:

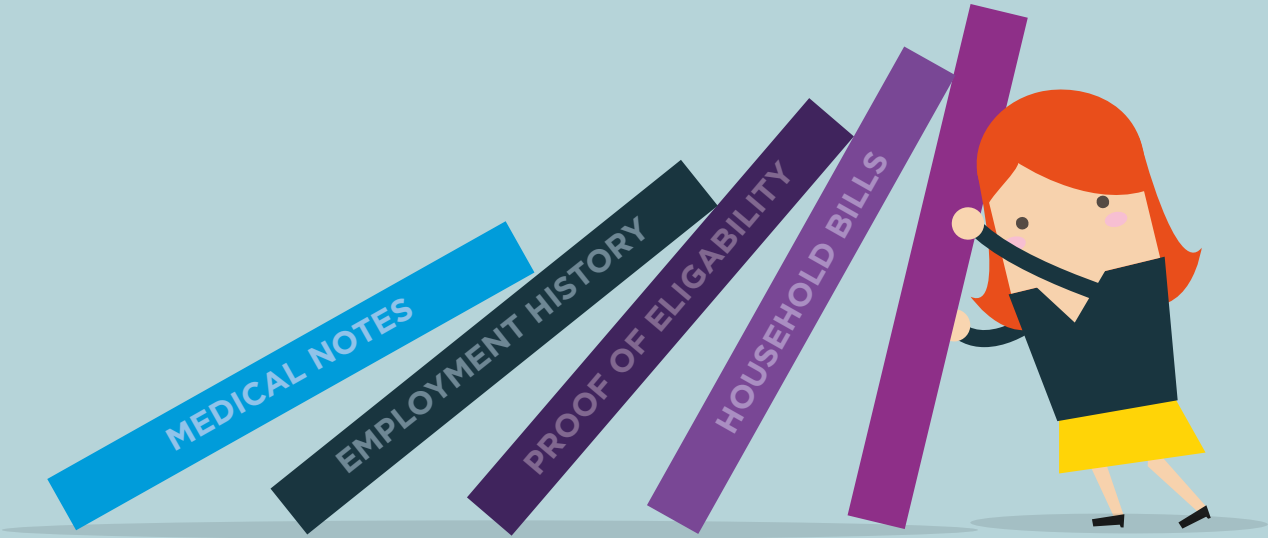
- Designing online forms so people can save their progress and return at a later time, and clearly communicate that this is possible to claimants, which would help those struggling with reduced concentration, memory problems or low energy
- Providing reminders of actions claimants should take and the relevant deadlines through a variety of channels – ideally using channels beyond telephone and post, which many people experiencing mental health problems struggle to use
- Offering advanced sight of interview questions to help claimants with mental health problems which make understanding and processing information harder than usual, and who may struggle to give an accurate answer to questions unless they've had a chance to prepare.

In some cases, people with mental health problems will experience symptoms so severe that even an accessible process won't suffice. To ensure the most vulnerable people are not left behind, we must ensure additional, targeted support is available to people with more complex needs, including people experiencing a mental health crisis or with severe and enduring mental health problems.

## Recommendations

We recommend that the government should:

- Amend Universal Credit Regulations to introduce a new easement for people receiving treatment for a mental health crisis
- Immediately provide adjustments to assessment processes for people with severe mental illness, following the model used for Health and Social Care assessments
- Simplify the reassessment process for people with severe mental illnesses.



## Introduction

The benefits system is intended to be a safety net, ensuring our basic needs are provided for when we are unwell, unable to find work or our income isn't enough to make ends meet.

Unsurprisingly, these challenging times can affect our mental health too – whether or not this is the reason for our claim. A third of Housing Benefit claimants (35%), and nearly half (47%) of adults aged 16-64 in receipt of some kind of out of work benefit have a common mental disorder, such as depression or generalised anxiety disorder. This rises to two thirds (66%) of people claiming Employment and Support Allowance (ESA), a benefit aimed at those unable to work due to poor health or disability. A substantial number of ESA claimants also demonstrate symptoms of more severe mental health problems:

- One in three screen positive for Post-Traumatic Stress Disorder
- One in eight (12%) screen positive for Bipolar Disorder
- One in seven tested positive for psychosis.

43% of ESA claimants also report that they have attempted suicide at some point in their lives, compared to just 7% of people not claiming ESA.<sup>2</sup>

These statistics show that a significant number of very vulnerable people rely on the benefits system. When it fails, lives are put at risk and can be lost.

"I was given ESA without an assessment but PIP took me to tribunal to fight for what I deserved... Things got so bad I made suicide attempts while waiting for my PIP brown envelope. I was so low and was shamed. I needed the help but wasn't being believed even with lots of supporting evidence from health professionals."

*Expert by experience*

Common symptoms of mental health problems include reduced concentration, increased impulsivity, memory problems and reduced planning and problem solving skills, all of which can make it harder to claim and manage benefits. In designing the benefits system, the government has to balance the needs of people claiming benefits, including the additional challenges people experiencing mental health problems might face and the additional harm they may experience when things go wrong, with the requirements of fairness and value to the taxpayer.

An additional challenge, however, is that the high prevalence of mental health problems among benefits claimants will not always be visible to staff – or even to claimants themselves. Half of ESA claims are specifically for a mental or behavioral disorder,<sup>3</sup> but with two thirds of claimants screening positive for mental health problems,<sup>4</sup> this implies that a third (31%) of people claiming primarily for a physical or sensory health problem are also experiencing a mental health problem, as illustrated in Figure 1.

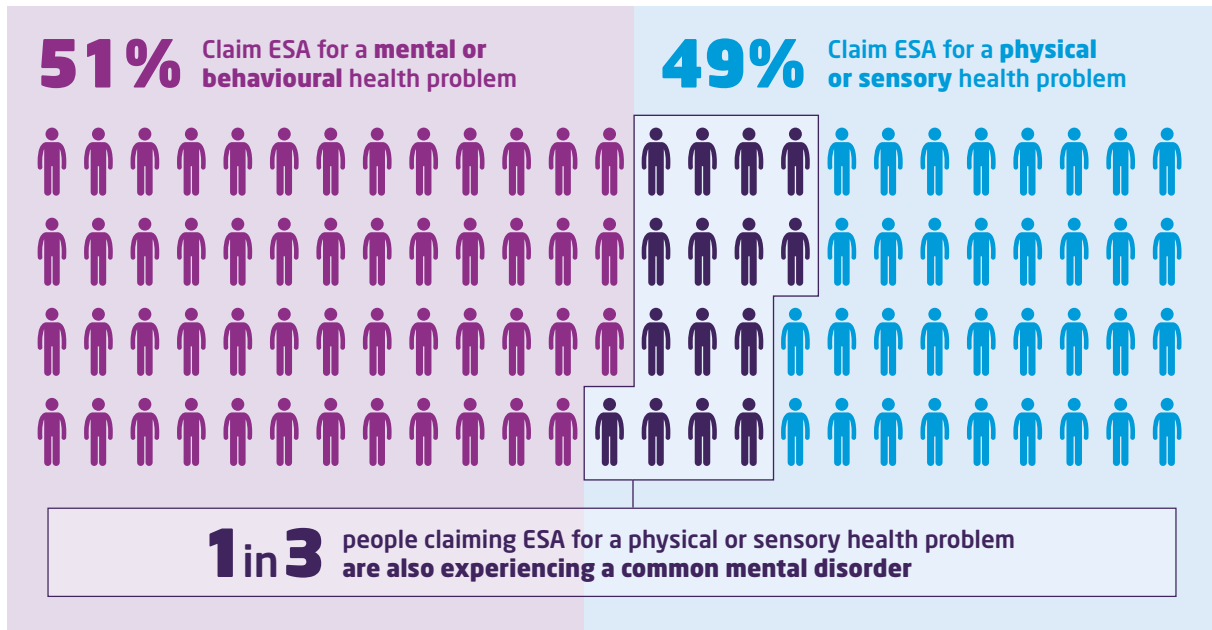
2. McManus S et al (eds.) Mental health and wellbeing in England: Adult Psychiatric Morbidity Survey 2014. NHS Digital. 2016.

3. Department for Work and Pensions (DWP). Employment and Support Allowance Caseload statistics, May 2018. Accessed through Stat-Xplore, January 2019.

4. McManus S et al (eds.) Mental health and wellbeing in England: Adult Psychiatric Morbidity Survey 2014. NHS Digital. 2016.



**Figure 1: Understanding the mental health of the population of ESA claimants**



Source: Money and Mental Health analysis of Department for Work and Pensions, Employment and Support Allowance statistics, May 2018, and Adult Psychiatric Morbidity Survey 2014.

Some of these claimants will not be aware they are experiencing a mental health problem.<sup>5</sup> Others may be aware of their mental health problems, but due to stigma or the difficulties of claiming for a mental health problem, prefer to claim for a comorbid physical health problem. This means that when aiming to provide an accessible benefits system, we cannot just focus on providing extra help to claimants who disclose a mental health problem, but need to make sure the system is accessible for everyone.

One way of doing this is to take a universal design approach: to design the system with the needs of those who are likely to have most difficulty navigating it in mind, on the understanding that if it works for this group, it will work for everyone else too. An example of

this approach from daily life is the dropped kerb. Rather than placing motors in wheelchairs so people could rise up to kerb level to rejoin the pavement after crossing a road, we lowered the kerb at crossing points. In doing so, as well as making life easier for people in wheelchairs, we also help people with limited mobility, with wheeled suitcases, and with children in pushchairs – meaning it helps most of us, at one time or another.

A universal design approach cannot fix all problems, however. Some people will still need additional help – like a person to help them see when the road is safe to cross. The benefits system might need to take a similar ‘twin track’ approach, designing the system to work for as many people as possible, with extra help available to those who need it most.

5. McManus S et al (eds.) Mental health and wellbeing in England: Adult Psychiatric Morbidity Survey 2014. NHS Digital. 2016.

## This report

In this report we present new research following the process of claiming benefits – from initial application to providing evidence and information, attending assessments, managing ongoing claims and challenging decisions – and assess how mental health problems can make claiming benefits more difficult. We recommend changes which could make the system more accessible.

While we recognise there are significant issues around the level of and delays in payments, and eligibility thresholds, a wealth of work already exists in this area.<sup>6</sup> In the interests of contributing something new to this debate, these issues are excluded from this project. Equally, some groups argue that the existing benefits system is so damaging as to merit a wholesale redesign. We agree the current system is not working, and would welcome a radical rethink. However, within this report we limit our recommendations to considering how to improve the current system, to make the greatest difference to people experiencing mental health problems in the present political environment.

In assessing the extent to which the benefits system is accessible, we consider both the extent to which people experiencing mental health problems are able to navigate systems and processes, and the extent to which they are able to achieve similarly good outcomes from doing so as people without mental health problems – in terms of the likelihood of receiving the correct decision for their level of health, and avoiding unnecessary distress.

This report draws on a scoping survey of 362 people with lived experience of mental health problems, followed by detailed surveys of:

- 617 people with lived experience of mental health problems, of whom 455 have claimed Personal Independence Payment (PIP), Universal Credit (UC), Housing Benefit (HB), Jobseeker's Allowance (JSA), Employment Support Allowance (ESA) or Council Tax Reduction (CTR) in the last two years
- 95 carers who have helped someone experiencing mental health problems with their benefits
- 73 people who work with people with mental health problems in a professional capacity.

6. Barnard H et al. UK Poverty 2018. Joseph Rowntree Foundation (JRF). 2018; Phillips T. Falling through the cracks: The widening gap between unemployment and benefit statistics. Resolution Foundation. 2018; Rahman A. Universal Credit for single disabled people. Citizens Advice. 2018.

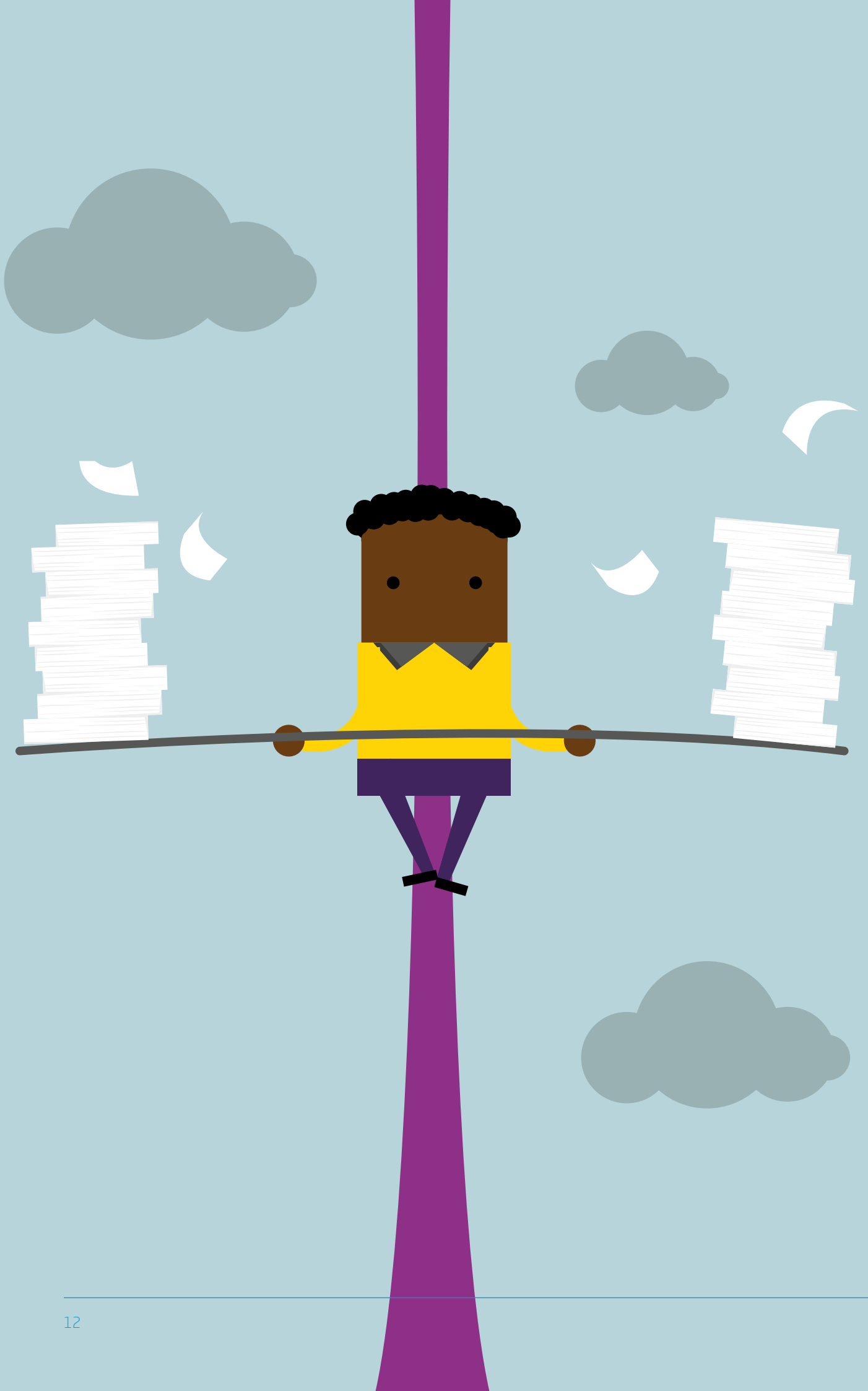
We also held an online focus group with seven people with lived experience of mental health problems to explore the issues in greater depth. Further details on methodology are provided in Annex A. Though much of the evidence collected relates to legacy benefits due to the limited progress of the UC rollout, we consider how our findings apply to UC, and make recommendations for both the design of UC and the 'Managed Migration' of claimants from legacy benefits to UC.

Following earlier work exploring how the cognitive and psychological symptoms of mental health problems can affect financial capability,<sup>7</sup> and assessing the implications for the accessibility of essential services (energy, water, telecoms and financial services),<sup>8</sup> in this report we:

- Provide context on the current state of the UK's benefits system and the challenges people experiencing mental health problems can face (section one)
- Detail specific issues with navigating the various stages involved in claiming and managing benefits (sections two to six)
- Identify opportunities for government to make the benefits system more accessible for people experiencing mental health problems (section seven).

7. Holkar M. Seeing through the Fog. Money and Mental Health Policy Institute. 2017.

8. Holkar M, Evans K and Langston K. Access essentials. Money and Mental Health Policy Institute. 2018.



## Section one: The context and the challenge

UK citizens are offered a range of benefits in times of need, including:

- **Support for people living on a low income.**  
Those who are unemployed may claim Jobseeker's Allowance (JSA), while people who are unable to work due to illness or disability may claim Employment and Support Allowance (ESA). Help with housing costs is also offered, for example through Housing Benefit (HB) and Council Tax Reduction (CTR). Six of these benefits (Housing Benefit, Jobseeker's Allowance, Employment Support Allowance, Income Support, Child Tax Credits and Working Tax Credits) were combined into Universal Credit by the Welfare Reform Act 2012
- **Specific support with the additional costs of living with a disability,** through Personal Independence Payment (PIP). Eligibility depends entirely on how much a person's illness or disability affects daily living activities, and not the claimant's income.

A core aim of Universal Credit is to simplify the complex legacy benefits system.<sup>9</sup> While many agree with this, there is a great deal of criticism about how UC is working in practice. Participants who had made the transition to UC described experiencing severe financial hardship, which invariably affected their mental health.

"When Universal Credit took just under fifty percent of my benefit for repayments to the Department for Work and Pensions, [it] took over four months to have sorted and I spent those months visiting the local food bank after being left with £25 to live on all month. This was the most damaging experience to my mental health."

*Expert by experience*

Several factors contribute to these problems, including the extension and intensification of conditionality in Universal Credit,<sup>10</sup> and delays in payments.

The rollout of UC is currently around six years behind schedule and has been delayed again as the government considers how best to transfer those currently receiving legacy benefits to the new system.<sup>11</sup> Just under 20% of claimants have currently been transferred.<sup>12</sup> With recent research suggesting the transition from Incapacity Benefit to PIP substantially disadvantaged people with psychiatric illnesses,<sup>13</sup> it is critical that care is taken to ensure that UC works for claimants experiencing mental health problems – both through the transition process and on an ongoing basis. As the claimant journey for UC retains many aspects of existing benefits processes, such as form-based applications, the need to provide evidence, and to attend appointments and assessments, there is much to learn from people's experience of the legacy system.

9. Gregory R. Checking in: applying and waiting for Universal Credit. 2018; Jitendra A. Left Behind: Is Universal Credit Truly Universal? The Trussell Trust. 2018; Brewer M, Finch D, and Tomlinson D. Universal Remedy: Ensuring Universal Credit is fit for purpose. Resolution Foundation. 2017.

10. Watts B et al. Welfare sanctions and conditionality in the UK. JRF. 2014.

11. Amber Rudd MP. Universal Credit: personal welfare. Speech delivered at Kennington JobCentre. 11 January 2019.

12. Money and Mental Health analysis of Department for Work and Pensions. Universal Credit statistics: claims, monthly starts and people on Universal Credit up to 13 December 2018. 2019.

13. Pybus K et al. Discrediting experiences: Outcomes of eligibility assessments for claimants with psychiatric compared to non-psychiatric conditions transferring to Personal Independence Payments in England. British Journal of Psychiatry. Forthcoming 2019.

## 1.1 The problems faced by people experiencing mental health problems

The legacy system is far from ideal. Up to 1.3 million families miss out on housing benefit entitlements, and up to £2.4 billion of available Income Support or ESA goes unclaimed.<sup>14</sup> When people who are unwell cannot gain access to appropriate benefits, there are significant personal and societal consequences.

Firstly, struggling to access benefits can leave people without sufficient income to meet their basic needs. Our research identified people who had cut back on essentials such as energy and food when they were unable to access benefits. In some cases people resort to high-cost credit to make ends meet, which can quickly lead to problem debt. In others, people turn to friends or family. While these loans are often helpful, they can also strain relationships and leave people vulnerable to coercion or abuse.<sup>15</sup> Where people are unable to access benefits when experiencing a mental health problem, they may return to work, even when they are not well enough to do so.<sup>16</sup>

This financial strain can seriously undermine a person's mental health. So, too, can the effort involved in navigating a complicated system, and the uncertainty as you wait for assessments, reassessments or the results of mandatory reconsiderations and tribunals. People who have struggled to access the benefits system tell us this can leave them feeling desperate, which can trigger suicidality.<sup>17</sup>

"I was hospitalised due to a suicide attempt a few hours after finding my Jobseeker's Allowance had been cancelled with no explanation."

*Expert by experience*

To understand the impact on our mental health of interactions with the benefits system, we adapted tools developed by the American Psychiatric Association to assess Social Anxiety and Specific Phobias, to assess levels of anxiety Research Community members experience when dealing with the benefits system. The results, illustrated in Figure 2, are striking.

Nine in ten (94%) participants exhibit some level of anxiety around engaging with the benefits system. More than four in ten (45%) reported symptoms indicative of severe or extreme anxiety. Over two thirds (67%) of survey participants reported feeling physical symptoms like racing heart, sweating, or trouble breathing, most or all of the time they were dealing with benefits agencies. Other common symptoms include avoiding contacting benefits agencies, feeling tense or experiencing moments of sudden fear, and needing help to cope, including from other people, superstitious objects or alcohol.<sup>18</sup>

The stress caused by the benefits system places greater strain on other public services, including mental health services. Many mental health professionals tell us problems managing benefits can have such a serious impact on a person's mental state and sense of security that it distracts completely from clinical care.<sup>19</sup>

"We can't get anywhere until benefit, housing and all that...is sorted out, because people are just not in the right mind-set to move forward until those basic needs are met."

*Mental health practitioner*

14. DWP. Income-related benefits: Estimates of take-up, data for financial year 2016/17. 2018.

15. Braverman R, Holkar M and Evans K. Informal borrowing and mental health problems. Money and Mental Health Policy Institute. 2018.

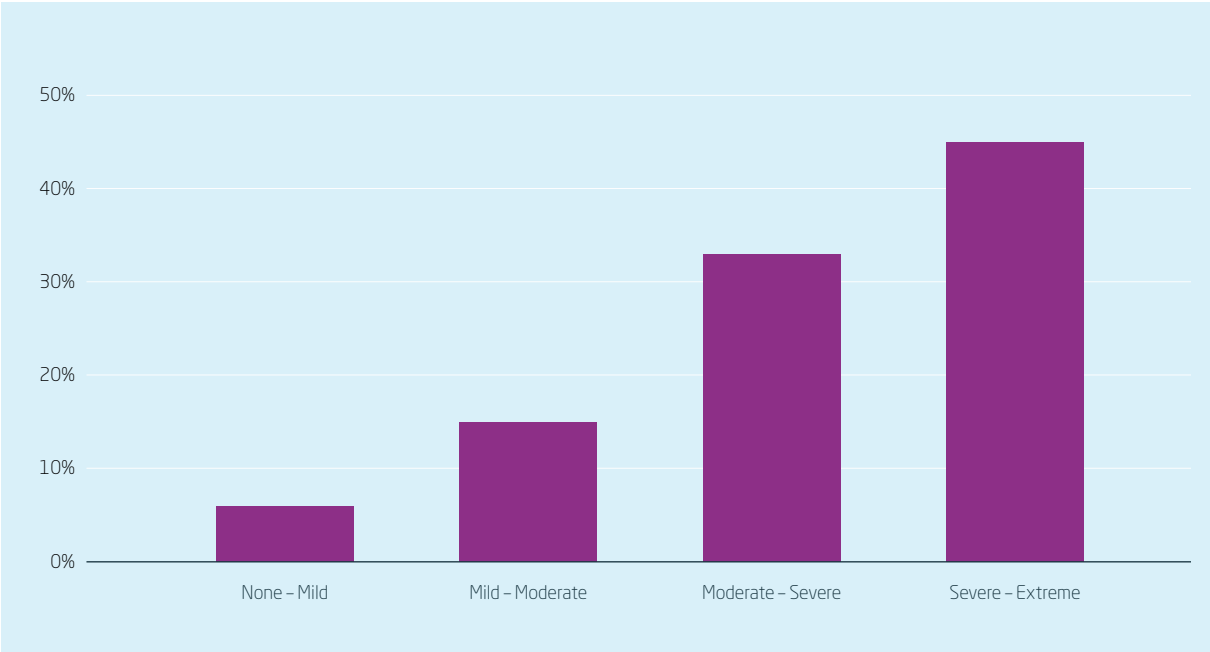
16. Bond N and Braverman R. Too ill to work, too broke not to. Money and Mental Health Policy Institute. 2018.

17. Bond N and Holkar M. A silent killer. Money and Mental Health Policy Institute. 2018.

18. Money and Mental Health survey. Base for this question: 417 people who have who have claimed ESA, HB, JSA, UC, CTR or PIP in the last two years.

19. Clarke T. Whose job is it anyway? Money and Mental Health Policy Institute. 2017.

**Figure 2: Levels of anxiety experienced by people with mental health problems when dealing with the benefits system**



Source: Money and Mental Health survey. Base for this question: 417 people who have claimed ESA, HB, JSA, UC, CTR or PIP in the last two years.

Financial insecurity resulting from problems accessing benefits can delay recovery from mental health problems, meaning the government faces greater health and social care costs and a higher benefits bill

in the long term. People who are unable to access benefits may also require more support from advice agencies, or friends and family, who may find providing this help stressful.

## 1.2 Why are people experiencing mental health problems struggling to access benefits?

Administering the benefits system invariably involves complex systems and processes, where people must provide detailed information on their circumstances to help officials reach a decision on their eligibility. A degree of friction in this process is inevitable – there will be forms to complete, appointments to attend, and other processes that involve effort and take time.

However, most people with a mental health problem will experience a combination of changes to the way they think, feel and behave, all of which can make it even harder to navigate the benefits system. Table 1 summarises some of the most common symptoms.

**Table 1: How the cognitive, psychological and behavioural changes associated with mental health problems can make navigating the benefits system harder**

What is the problem?	What is the impact?
<b>Difficulties understanding and processing information</b>	People may take longer to process information, or require additional prompts to provide the relevant facts. This can make answering questions accurately much harder, particularly where detailed information is needed to assess entitlements.
<b>Memory problems</b>	Difficulties recalling information can make answering questions on forms or in assessment interviews tricky.
<b>Reduced planning and problem solving skills</b>	Faced with a difficult problem, people can struggle to work out what actions they should take to resolve it. This can make getting through lengthy and complex processes difficult.
<b>Reduced attention span</b>	Concentrating on a task for a prolonged period of time, such as filling in a long form, can be difficult.
<b>Social anxiety and communication difficulties</b>	Many people experiencing mental health problems struggle with some forms of communication. Previous Money and Mental Health research, focusing on essential services, found that half of people with a mental health problem struggle to use the telephone, and one in six struggle to open post <sup>20</sup> – it is likely this group experience similar difficulties communicating with benefits agencies.
<b>Increased impulsivity</b>	Increased impulsivity can mean people act without their usual degree of thought or attention.
<b>Depleted energy and motivation</b>	Low energy can make it difficult to complete basic self care tasks such as washing and eating. Finding the motivation to complete the complicated task of navigating the benefits systems can be impossible for some people.

Source: Money and Mental Health Policy Institute

20. Holkar M, Evans K and Langston K. Access essentials. Money and Mental Health Policy Institute. 2018.



### 1.3 Mapping the pain points

Through detailed thematic coding and analysis of qualitative data collected through this project, we have identified three ways in which these challenges make it harder for people experiencing mental health problems to navigate the benefits system:

#### 1. Complex and demanding administrative processes

To claim and manage benefits, people must complete a range of forms and provide certain types of evidence. For a person experiencing a mental health problem which affects their attention span, ability to process information, short term memory or motivation, navigating these lengthy processes can be nightmarish.

#### 2. Inaccessible appointments and communications

People claiming benefits need to be able to attend appointments and assessments, and make and respond to enquiries. Many mental health problems make these interactions particularly difficult. Agoraphobia, a fear of being in situations where escape is difficult, can make leaving the house and using public transport to reach appointments impossible. Social anxiety can seriously impact a person's capacity to make or answer queries. People with post and phone phobia may well not receive information about the actions they need to complete in order to receive their benefits in a timely way.

#### 3. Relationship dynamics

There is inevitably a power imbalance between claimants and government agencies. For people experiencing mental health problems, this imbalance is more dramatic because of the feelings of powerlessness, shame, and low motivation that are so often part of mental ill health. For people with severe mental illnesses, paranoia and delusions can make relating to authorities impossible.

Through the next five sections of the report, we examine how these challenges affect people experiencing mental health problems across five different parts of the benefits system:

- Section two – initial application
- Section three – providing information and evidence
- Section four – assessments
- Section five – ongoing management
- Section six – challenging decisions.



## Section two: Initial application

Applying for a benefit can be a demanding, multi-step process. People experiencing financial difficulties as a result of ill health will often have to apply for several benefits at once, even under Universal Credit, if they also qualify for PIP or CTR.

### 2.1 Complex and demanding administrative processes

People need considerable concentration and clarity of thought to sift through vast amounts of information to work out what benefits they might be entitled to and how to apply. For some people experiencing mental health problems, this proves a significant barrier. Four in ten (40%) survey participants said they delayed or decided not to claim ESA when they thought they might be eligible,<sup>21</sup> and half (51%) said they had delayed or decided not to make a PIP claim.<sup>22</sup>

"Not been well enough or had enough concentration to understand what I am entitled to [or] how to apply for benefits."

*Expert by experience*

To apply, people then usually need to complete a paper or electronic form. Nearly every participant who had claimed PIP (97%) found the forms difficult<sup>23</sup> and nine in ten (91%) struggled to complete ESA forms.<sup>24</sup>

Benefit application forms are notoriously complicated, with some forms over 50 pages long, which can be incredibly daunting for people experiencing low energy. Participants told us they often find both online and paper forms overwhelming.

"The application form was about 30 pages long which was very off-putting to start with because keeping concentration for long periods is very difficult for me."

*Expert by experience*

Questions on both PIP and ESA/UC forms tend to focus on people's physical ability to carry out activities, such as moving around, preparing a meal or picking things up. Participants said questions aimed at understanding mental health problems do not cover the full range of their symptoms, so they often have to translate how their mental ill health affects their ability to complete tasks.

"All of the questions about how your health is affected by your illness were geared towards having a physical disability. I found it extremely difficult to explain that although I can physically do certain tasks, it is the motivation, ability to remember, communication, feelings of anxiety etc that affects me."

*Expert by experience*

<sup>21</sup>. Money and Mental Health survey. Base for this question: 427 people with lived experience of mental health problems.

<sup>22</sup>. Ibid. Base for this question: 445 people with lived experience of mental health problems.

<sup>23</sup>. Ibid. Base for this question: 242 people who have claimed PIP in the last two years.

<sup>24</sup>. Ibid. Base for this question: 251 people who have claimed ESA in the last two years

ESA and PIP applications also often require claimants to repeatedly focus on their mental distress, which can be emotionally exhausting and demoralising.

"You have to write down all your most upsetting and distressing experiences and it is quite traumatic and leaves you feeling shaken."

*Expert by experience*

People reported frustration at having to give basic information, such as income details, time and again for each benefit they claim – a tiring experience for a person experiencing low energy as a result of a mental health problem.

"When applying for housing and council tax benefit, child tax credits etc., every association wants the same information."

*Expert by experience*

Although the Department for Work and Pensions (DWP) is committed to exploring data sharing between ESA/UC and PIP and across the health and welfare systems, this intention is not yet reflected in the experiences of claimants.<sup>25</sup>

## 2.2 Inaccessible communication channels

Most benefits restrict claimants' choice of communication channels. People applying for UC due to ill health, for example, must complete an online form, then a paper one. PIP applicants must make a phone call, then complete a paper form. Three quarters (75%) of people with mental health problems struggle with at least one communication channel when communicating with essential services firms,<sup>26</sup> and many participants reported similar difficulties making telephone calls or opening post from the DWP. Over half (53%) said they always or often need help talking to benefits agency staff on the phone.<sup>27</sup>

"When I have had to use the phone it stresses me out. I stammer and stutter [and] cannot get my words out. I get flustered and want to give up."

*Expert by experience*

Which communication channel is problematic varies from person to person, and may change as a person's mental health fluctuates. A restricted choice of channels can therefore make it hard for people to engage with particular tasks, meaning claims are delayed or not completed. While email and text messages are offered as alternatives, public awareness of this and take up is very low, with both accounting for just 3% of transactions with the DWP in 2017/18.<sup>28</sup>

<sup>25</sup>. DWP. Single Departmental Plan. 2019.

<sup>26</sup>. Holkar M, Evans K and Langston K. Access essentials. Money and Mental Health Policy Institute. 2018.

<sup>27</sup>. Money and Mental Health survey. Base for this question: 374 people who have claimed ESA, HB, JSA, PIP, UC or CTR in the last two years.

<sup>28</sup>. DWP. Claimant Service and Experience Survey 2017/18. 2019.

### Summary

Challenges around making initial benefits applications for people experiencing mental health problems include:

- Having to sift through vast amounts of information to understand eligibility
- Long and repetitive application forms
- Confusing and physical health-centric questions, requiring a level of mental dexterity to interpret and answer
- Limited choice of communication channels which make completing an application difficult.



## Section three: Providing information and evidence

People must provide information and evidence to support their application and prove eligibility for benefits. This may include medical evidence, financial information, and proof of income and identity documents. Claimants who do not provide the correct information at the right time can wait longer for decisions and risk the wrong decision being made.

### 3.1 Complex and demanding administrative processes

Finding the right pieces of information and evidence can be inordinately difficult for people experiencing mental health problems which affect planning and problem solving. Three quarters (74%) of survey participants struggled to know what information to provide, with some reporting that guidance around the evidence that must be submitted is often unclear, putting them at a disadvantage when their mental health problems affected their comprehension. Low motivation, difficulties concentrating and problems opening post can also make locating documents difficult. 82% of survey participants struggled to locate the information required.<sup>29</sup>

"My paperwork is a mess, and I have problems finding the right letters/information. I get very confused [about] which one of the loads of letters I have received from child benefit, child tax credits, council tax, etc. is the one I need."

*Expert by experience*

Documents must be submitted to tight deadlines if claims are not to be cancelled, which can be challenging for people experiencing memory problems or low motivation.

### 3.2 Relationship dynamics

People claiming benefits related to ill health must provide medical evidence to prove how their health conditions meet eligibility criteria. This could include prescriptions, care plans and medical reports, but to be useful they must offer information about how a person's medical condition affects their daily life. This can be difficult for a person experiencing a mental health problem to obtain. Many manage their conditions with minimal support or do not meet thresholds for secondary care services. Their GP may not see them frequently, and could have only minimal information about how their mental health problem impacts their daily activities.

"For myself with a long-term health condition, I've not seen [a medical professional] for years, as there is nothing else apart from self-management and medication."

*Expert by experience*

While the DWP also ask for contact details for health professionals involved in a person's care, they warn that these people will not always be contacted.<sup>30</sup> Even where the DWP do contact health professionals, it can be difficult for clinicians to provide relevant information on the functional questions asked, and to engage with the lengthy guidance provided.

Given the importance of benefits claims to the financial and emotional wellbeing of claimants, and the anxiety people feel around interactions with the DWP, the process of providing medical evidence can feel highly uncertain to claimants. As a result, some people ask healthcare professionals to provide additional evidence. Unlike evidence requested directly by the DWP, this is not covered by medical professional's NHS contracts, and they may charge service users for the provision of this information.

<sup>29</sup>. Money and Mental Health survey. Base for this question: 403 people who have claimed ESA, HB, JSA, UC, CTR or PIP in the last two years.

<sup>30</sup>. DWP. Personal Independence Payments (PIP) Handbook. 2018; DWP. Universal Credit Capability for Work Questionnaire (UC50). December 2017; DWP. ESA Capability for Work Questionnaire (ESA50). May 2018.

## Summary

- Low motivation, difficulties concentrating, reduced planning and problem solving skills and aversions to opening post can all make it more difficult for people experiencing mental health problems to provide the DWP with information and evidence regarding their claim.
- Three quarters of survey participants (74%) didn't know what information they should provide, and four in five (82%) had difficulty finding the right documentation.
- The process of providing medical evidence is deeply stressful for people experiencing mental health problems. Many people are not under the care of secondary services who could provide information about the nature of their illness, and GPs may have a much more limited understanding of the functional impacts of a person's condition.
- Mistrust in the DWP's evidence gathering procedures means some people with mental health problems seek additional evidence from healthcare professionals, even where this incurs additional costs they can ill afford.





## Section four: Assessments

The DWP typically check claimants' eligibility for PIP and ESA through face to face medical assessments carried out by assessors employed by private companies on behalf of the DWP. The assessment system has received widespread scrutiny and many problems have been identified.<sup>31</sup>

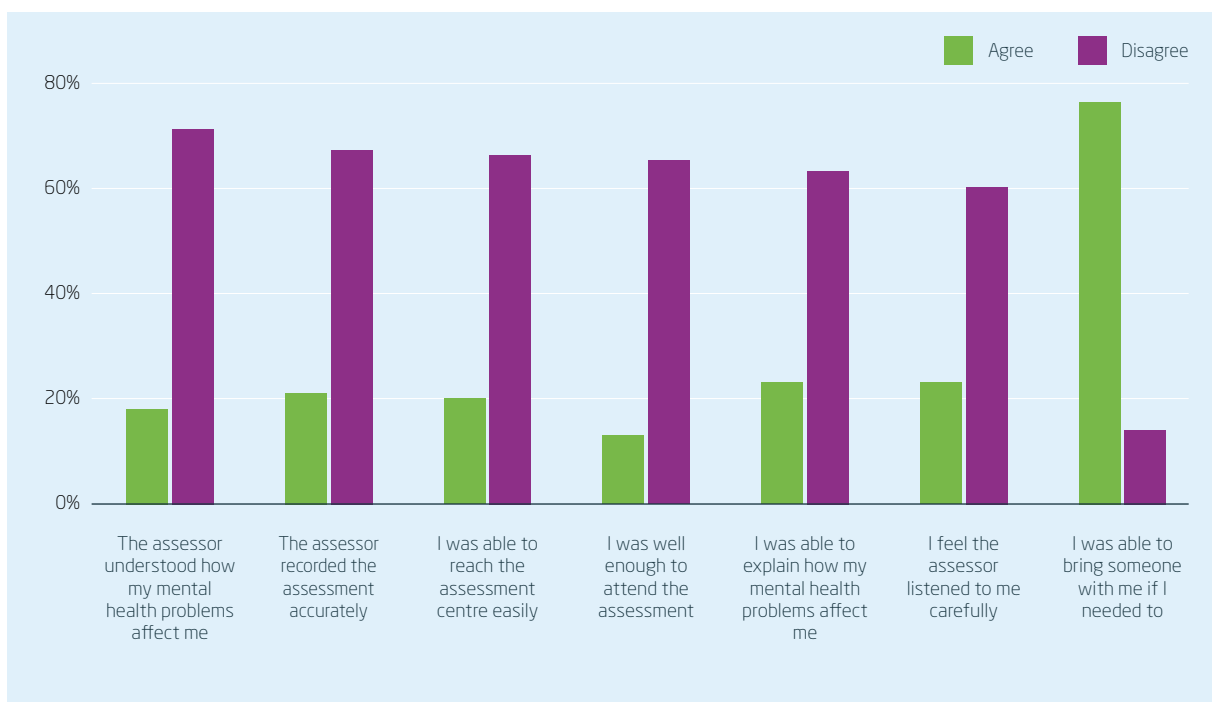
Nine in ten survey participants (93%) reported their mental health deteriorated in anticipation of the assessment and 85% said their mental health deteriorated afterwards.<sup>32</sup>

"My mental health is bad at the best of times but it crashes during, and remains bad, for at least 4 or 5 months after any reassessment."

*Expert by experience*

Figure 3 indicates the negative experiences many claimants have in assessments.

**Figure 3: Reported experience of medical assessments for benefits eligibility**



Source: Money and Mental Health survey. Base for this question: 417 people who have claimed ESA, HB, JSA, UC, CTR or PIP in the last two years.

<sup>31</sup>. Litchfield P. An Independent Review of the Work Capability Assessment – year five. 2016; Gray P. The Second Independent Review of the Personal Independence Payment Assessment. 2017.

<sup>32</sup>. Money and Mental Health survey. Base for this question: 259 people who have experienced a medical assessment in the last two years.

#### 4.1 Inaccessible appointments

Claimants who miss assessments can face serious consequences: ESA claimants who miss an assessment are deemed capable of work, and PIP claimants' claims will be closed and they have to start the application process again.

Claimants are told when and where their assessment appointment will take place. There is little flexibility for them to influence the date, time or place of their assessment. Two thirds (66%) of participants reported that they struggled to reach the assessment centre.<sup>33</sup> Home visits are available for both benefit assessments, but the claimant must provide medical evidence of need, invoking all the problems identified in section three.

This rigidity particularly affects people with mental health problems, who may struggle to remember appointments or leave the house because of anxiety or panic. Nearly two thirds (65%) of survey participants told us they were not well enough to go to their appointment.<sup>34</sup> Being ill on the day means either trying to rearrange an appointment, with all the difficulties that involves, or attending while unwell, which could reduce a person's ability to articulate their needs and reduce the likelihood of a correct decision.

Seven in ten people (69%) said they always or often needed to be accompanied to appointments and assessments.<sup>35</sup> A companion can help someone to reach the assessment centre, offer reassurance or advocate for someone less able to articulate their needs. While most participants said they were able to bring someone with them to their assessment if they needed to, one in seven (14%) reported that they were unable to do so.<sup>36</sup> Without this support, a person experiencing a mental health problem might be less able to self-advocate and obtain an accurate decision.

#### 4.2 Relationship dynamics

Mental health problems are often associated with feelings of guilt and shame, which can make it harder for a person to self advocate. Sometimes people will not share the full extent of their symptoms due to feelings of shame. Cognitive challenges associated with mental health problems may also make it harder for people to explain how their illness affects them in response to specific questions, particularly when they are not given foresight of the questions or an opportunity to prepare.

These challenges experienced by people with mental health problems, together with the attitude and knowledge of assessors, can create a toxic cocktail. 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.<sup>37</sup>

Lack of skills on the part of the assessors appears to be part of the problem here. Firstly, although all assessors receive some training in mental health, there is no requirement for them all to have direct experience or detailed knowledge of mental health issues, and only a minority are mental health specialists.<sup>38</sup> This may make it harder for assessors to understand the challenges claimants face, particularly when a person is struggling to express themselves in a difficult situation. Assessors may be less able to make inferences about a person's capabilities than they are with a person experiencing a physical health problem.

Participants explained how judgements were sometimes made about their capability based on spurious evidence, such as making eye contact, being well-groomed or looking after a pet. Although fluctuating health conditions are covered by legislation, there was a lack of understanding of how fluctuations in mental illness can

33. Money and Mental Health Survey. Base for this question: 262 people who have undergone a medical assessment in the last two years.

34. Ibid. Base for this question: 264 people who have undergone a medical assessment in the last two years.

35. Ibid. Base for this question: 361 people who have claimed ESA, HB, JSA, PIP, UC or CTR in the last two years.

36. Ibid. Base for this question: 258 people who have undergone a medical assessment in the last two years.

37. Ibid. Base for this question: 266 people who have undergone a medical assessment in the last two years.

38. Written evidence from ATOS Independent Assessment Services in House of Commons Work and Pensions Committee. PIP and ESA assessments: claimant experiences. Fourth Report of Session 2017-19. 2018.

affect people's capacity to carry out tasks or their need for care.

"Worst of all [is] that it is an illness that fluctuates, and your physical state fluctuates with your mental state. I can be ill for months and then have 3 days or 3 weeks feeling good, then be ill for months again."

*Expert by experience*

As few assessors have clinical backgrounds in mental health practice, participants' experiences of assessments not being suitably tailored to meet their mental health needs is unsurprising.

A lack of trust and feeling of unease on the part of claimants is also created by the way assessors conduct assessments. Six in ten participants (60%) felt that the assessor did not listen to them carefully,<sup>39</sup> and many found assessors' manners to be unsympathetic, judgemental and uninterested, so felt unheard and more distressed.

Participants said assessors often responded to their difficulties inappropriately. An important aspect of mental health awareness is understanding that those

experiencing poor mental health often need more time to answer questions, but this was not often offered.

"I found it incredibly stressful and got quite flustered, and my mind went blank and I couldn't remember things, so [I] had to keep saying either "I can't remember" or "I don't know". The assessor gave the impression that she thought I was making it up, but I wasn't."

*Expert by experience*

"Assessor asked lots of questions without wanting to wait for a full answer. He was impatient with me, and [my] support worker had to answer most [questions] for me."

*Expert by experience*

Given the importance of these assessments to the claimant, these attitudes and behaviours on the part of assessors can create fear and a sense of distrust in the process – which in turn can make it harder for a person experiencing a mental health problem to participate.

## Summary

- Nine in ten (93%) people said their mental health deteriorated in anticipation of the assessment and eight in ten (85%) said their mental health deteriorated afterwards.
- People experiencing mental health problems are disadvantaged by inflexibility around times and places for assessment appointments.
- Seven in ten (71%) people said their assessor did not understand how their mental health problems affected them. People reported not being given enough time and experiencing their assessor's manner as unsympathetic, judgemental and uninterested. This has created an atmosphere of mistrust in this part of the application process, which can make it even harder for a person experiencing a mental health problem to self-advocate.

<sup>39</sup>. Money and Mental Health survey. Base for this question: 260 people who have undergone a medical assessment in the last two years.



## Section five: Ongoing management

Even once a person has had their benefit claim accepted, challenges remain for claimants experiencing mental health problems, particularly around complying with conditionality and managing payments.

### 5.1 Complex and demanding administrative processes

#### Complying with conditionality

People claiming income replacement benefits (JSA, ESA, UC) are required to comply with conditions, unless they are assessed as having limited capacity for work related activity. Conditions can involve a range of appointments to attend and tasks to complete, such as CV writing, searching and applying for jobs, or undertaking training. People experiencing mental health problems face two challenges with regards to conditionality:

#### 1. Understanding their commitments and ensuring they are appropriate

For some people experiencing a mental health problem which affects their executive functioning or memory, a conversation or a signed contract will not be enough for them to understand and remember what they need to do. They may need reminders and repeated explanations, which require staff to have sufficient awareness of mental health issues to respond appropriately.

"When I say that I am sorry but I don't understand some things, they can get very abrupt like I am wasting their time."

*Expert by experience*

The high stakes involved, combined with feelings of shame and embarrassment, can lead people experiencing mental health problems to agree to inappropriate conditions, which they struggle to comply with.

"I was forced into a job by the JobCentre, who told me I would be sanctioned if I didn't accept it. I left the job as the stress affected my depression, and [I] was sanctioned for 3 months, despite me trying to explain why."

*Expert by experience*

#### 2. Fulfilling conditions

Benefit conditions can be demanding, particularly if claimants have been placed in the wrong group after assessment. Attending appointments, a substantial part of conditionality, can be particularly difficult for people who experience memory problems, agoraphobia or social anxiety as part of their mental health problem. Only 17% of survey participants said appointments were always or often easy to get to. Some people experiencing mental health problems may also find certain times of day, particularly early mornings, more difficult. This is not always taken into account, with 57% reporting that appointments are rarely or never at a convenient time.<sup>40</sup>

Fluctuating mental health problems may also affect a claimant's ability to comply with work search conditions if, for example, a period of low mood makes completing a set number of hours of job search impossible. Guidance does allow some

40. Ibid. Base size for this question: 339 people who have claimed ESA, HB, JSA, PIP, UC or CTR in the last two years.

flexibility around conditionality, but claimants must be able to explain their reasons for not complying, which can be difficult for a person experiencing a mental health problem, due to a lack of self confidence or problem solving capabilities. If a person does not feel comfortable disclosing their mental health problems to JobCentre staff, or is unaware they are unwell, this may be interpreted as wilful non compliance, resulting in a sanction.

"When a service user is late or just does not appear for an interview regarding benefits, the staff think the service user is working on the side, but in real life, the patient has had or is experiencing a psychotic episode."

*Practitioner*

Budgeting and planning skills can be compromised in people experiencing poor mental health. Impulsivity is a recognised symptom of conditions such as bipolar and some personality disorders,<sup>41</sup> and many people experiencing poor mental health find their budgeting and planning skills compromised. The challenges involved in managing UC payments for this group can leave them vulnerable to housing arrears and homelessness. While the government has announced steps to address this, including offering direct payments of rent to landlords and more frequent payments, the criteria for being offered this are stringent.<sup>42</sup> The government has promised action to ensure more frequent and direct payments are more easily available to claimants,<sup>43</sup> but only time will tell if this has been effective.

### Inflexible payments

Participants also reported difficulties managing inflexible benefit payments, and identified two additional and significant barriers with the introduction of UC:

1. UC payments are made monthly, rather than the fortnightly payments for ESA and JSA
2. Housing payments are now paid directly to tenants, who then have to pay their landlord, rather than being made directly to landlords under HB.

### Managing multiple benefits

The challenges of managing benefits are magnified when people are managing multiple claims at the same time. Keeping track of each claim at different stages of the process, and ensuring compliance with conditionality, can prove impossible. The intention behind UC is to simplify managing benefits by reducing the number of claims people need to make. However, several benefits, such as PIP and CTR, remain outside UC's remit, so people experiencing mental health problems will need to continue to manage multiple claims.

41. American Psychiatric Association. Diagnostic and statistical manual of mental disorders (DSM-5). American Psychiatric Publishing. 2013.

42. Universal Credit: Personal Budgeting Support and Alternative Payment Arrangements. Guidance. V.8 2018.

43. Amber Rudd MP. Universal Credit: personal welfare. Speech delivered at Kennington JobCentre. 11 January 2019.

## Summary

- Conditionality requirements can be hard to understand and demanding to fulfil for claimants experiencing mental health problems.
- Getting to appointments often proves a particular hurdle, while fluctuating mental health conditions can make complying with work search or preparation requirements much more difficult. This is particularly problematic where claimants are unaware of undiagnosed mental health problems, or have not disclosed their mental illness to JobCentre staff.
- A lack of understanding of mental health problems among staff can lead to non compliance being met with sanctions.
- These difficulties are magnified for people managing multiple claims at the same time.





## Section six: Challenging decisions

With such a complex benefits system, it is inevitable that decisions about awards, levels of benefits or sanctions are sometimes incorrect. However, the number of successful challenges is worryingly high. Between January and March 2018, two in five appeals (39%) were upheld.<sup>44</sup>

The challenges facing people experiencing mental health problems in providing evidence, attending assessments and meeting ongoing conditionality, discussed in sections three to five, suggest that decision makers may be less likely to make accurate decisions for this group of claimants. The experience of our survey participants reflects this: four in five (81%) said that they had been unhappy with a benefits decision.<sup>45</sup> Adverse decisions can cause considerable mental distress.

"I was physically sick when the original decision came through, and went downhill health wise to feeling suicidal."

*Expert by experience*

People have to make a difficult choice either to accept or challenge the decision. While the DWP's figures suggest challenging a decision may be worthwhile, this can be a particularly daunting prospect for a person experiencing a mental health problem which reduces their sense of self-efficacy or impairs problem solving skills.

### 6.1 Complex and demanding administrative processes

Assessing whether an appeal may be successful requires:

- Access to information on which decisions are made
- Accurate records of assessments and evidence
- Transparent guidelines.

Participants told us of difficulties in all three areas.

#### Poor access to information

In order to decide whether they have a case for challenging a decision, people first need to understand why that decision has been made. ESA and PIP decisions are made on the basis of medical evidence and information provided at assessment interviews. However, copies of these assessment reports are not automatically provided with decision letters, so people need to ask for a copy before they can decide whether or not to appeal. This eats into the strict timescales to request a mandatory reconsideration or appeal.

"I wrote a letter asking for a reassessment and explanation of my assessment. This was last February and [I'm] still waiting for a reply from them."

*Expert by experience*

44. DWP. Employment and Support Allowance: Work Capability Assessments, Mandatory Reconsiderations and Appeals. 2018.

45. Money and Mental Health survey. Base for this question: 363 people who have claimed ESA, HB, JSA, PIP, UC or CTR in the last two years.

### Inaccurate records

Participants told us that on receiving copies of their assessments, they frequently found there was a huge disparity between their mental health needs and those that had been recorded. Memory problems associated with mental health problems may mean people struggle to remember the detail of their assessment sufficiently well to dispute the assessor's report, particularly if they were distressed at the time.

"My PIP review led to a reduction from enhanced rate PIP to standard rate. My illness has not changed at all, in fact I am worse, so this was down to the recording inaccuracies of the assessor and the lack of understanding of some parts of my condition – some parts that affect me deeply did not even get asked about, or assumptions were made."

*Expert by experience*

### Inadequate guidelines

Participants told us the guidelines around how to challenge benefit decisions lacked transparency due to being written in a legalistic way that can be difficult to understand. Interpreting this guidance and applying it to specific cases is incredibly difficult, requiring a keen ability to assimilate and decipher complex information, a cognitive skill people who are experiencing mental health problems may struggle with.

"I had to get someone to help me and do my mandatory reconsideration for me. I tried to do it myself but couldn't...I was left without money for around 12 weeks, which made me very ill, and [I] considered taking my life many times."

*Expert by experience*

Claimants can make an audio recording of their assessment interview, with prior permission. However, the DWP regulations permitting audio recordings are so strict, involving old fashioned equipment, that this is usually an impossibility.<sup>46</sup>

<sup>46</sup>. DWP. PIP assessment guide part 1: the assessment process. 2018; DWP. Employment and Support Allowance – Work Capability Assessment. Audio Recording of face-to-face assessments policy. 2013.

## 6.2 Relationship dynamics

### Feeling unable to challenge the system

All claimants seeking to challenge the system are extremely likely to be in a disadvantaged position in terms of their legal knowledge and experience. To go through the process alone requires persistence and motivation, together with high level cognitive skills which people experiencing mental health problems may be less likely to have. But, with the demise of legal aid for welfare benefit appeals and overstretched advice services, help can be hard to find.<sup>47</sup>

Claimants face an impossible predicament, with two stark choices:

- Accept the decision and survive on a reduced income
- Challenge the decision and risk a huge toll their mental health.

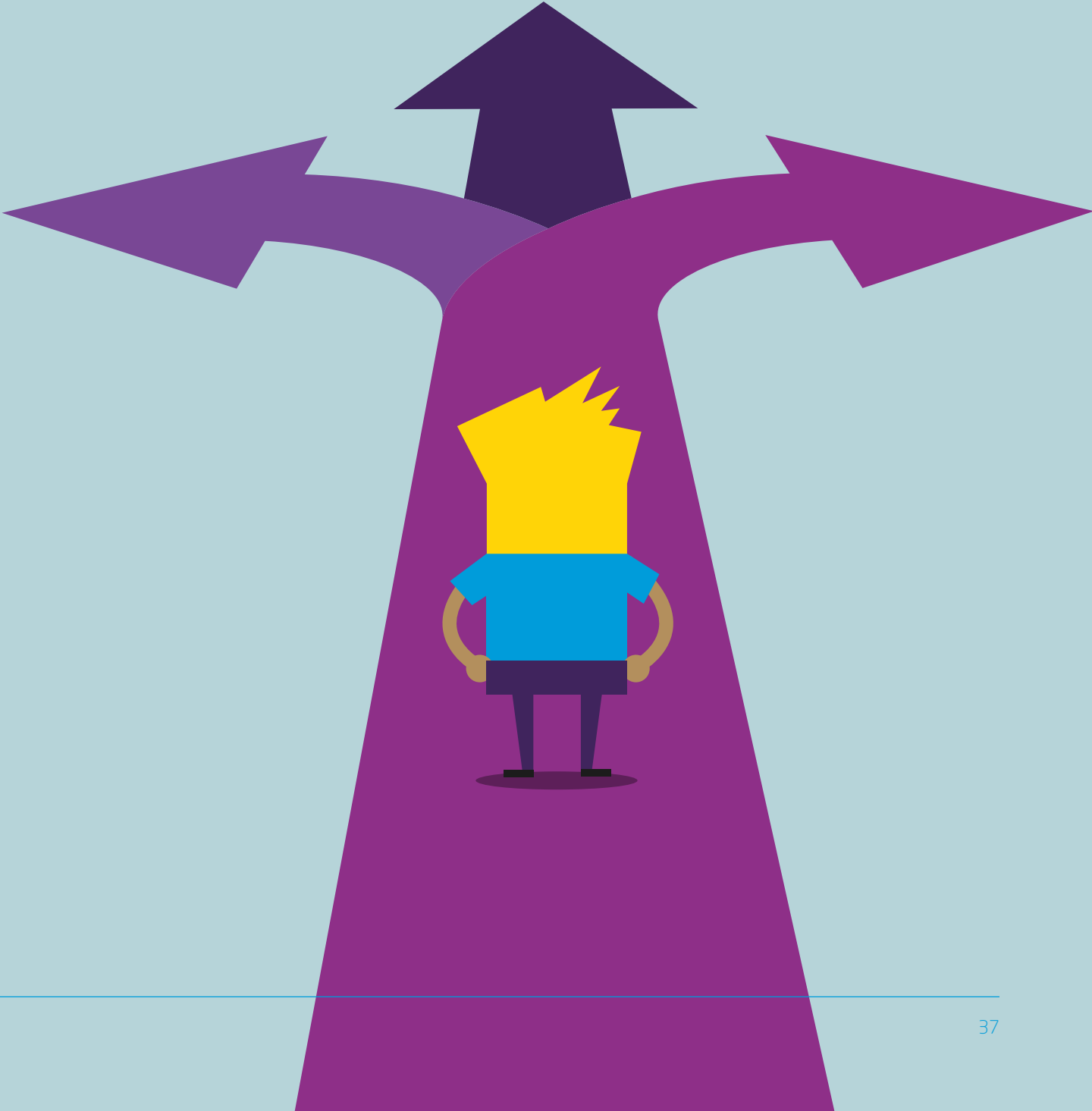
"The report was so wrong on so many things. I had my PIP reinstated eventually but not at the previous higher rate... I couldn't compromise my health any further, so accepted the lower level, which leaves me struggling week to week."

*Expert by experience*

### Summary

- 81% of participants said that they had been unhappy with a benefit decision.
- Challenging these decisions can be difficult. People feel ill equipped to challenge a system particularly where there is an imbalance between legal knowledge, process and understanding between claimant and benefits agency.
- People with mental health problems can experience difficulties with memory and attention span. These challenges mean that recalling information shared at assessment can be hard, and people are reliant on written records and audio recordings to understand the basis on which benefit decisions have been made.
- People are not routinely provided with access to full assessment reports or audio recordings, maintaining the asymmetry of power.

<sup>47</sup>. Sigafos J. The impact of legal aid cuts on advice-giving charities in Liverpool: first results. Charity Law & Policy Unit, University of Liverpool. 2013.



## Section seven: Conclusion and recommendations

Navigating the benefits system is inherently challenging. However for people experiencing mental health problems this can be significantly more difficult. The effects of mental health problems, combined with the design of the benefits system, mean people experiencing mental health problems can:

- 1. Struggle to identify which benefits they are entitled to and submit an initial application**
- 2. Have their application incorrectly declined** – the design and phrasing of application and assessment questions make it difficult for people experiencing mental health problems to articulate and evidence how they meet eligibility criteria
- 3. Disengage from the process** – people may have to start again if they miss tight deadlines or do not attend interviews. In some cases people become overwhelmed and respond by disengaging entirely.

Our research shows that, in many ways, legacy benefits exacerbate mental health problems by making people battle complex administrative processes, through inaccessible communications channels, against a backdrop of mistrust.

It does not have to be this way. There is much that benefits agencies can do to ensure claimants experiencing mental health problems can access their benefits efficiently.

Our recommendations are split into two parts:

- A. A set of universal design amendments that would make the benefits system more accessible for people experiencing mental health problems, whether these are the reason for their claim or not.**
- B. Specific recommendations to support people who are experiencing a mental health crisis, or with severe mental illness, who may need additional help to navigate the system even if baseline accessibility is substantially improved.**

### 7.1 Universal Design amendments

The concept of universal design involves understanding the barriers people may face in accessing a system or process, and rather than trying to identify and offer specialist support to those people, finding ways to change the system so the standard version works for them – and everyone else.

We believe universal design style changes could help improve the accessibility of the benefits system for people experiencing recognised and unrecognised mental health problems.

Table 2 sets out a summary of our recommendations.

**Table 2: Universal design recommendations to improve the accessibility of the benefits system for people experiencing mental health problems**

Problem with the benefit system	Why the system is more difficult for people experiencing mental health problems	Universal design response: <i>The DWP and local authorities should...</i>
<b>Complex and demanding administrative processes</b>	<ul style="list-style-type: none"> <li>• Difficulties processing information and clarity of thought</li> <li>• Short term memory problems</li> <li>• Reduced planning and problem-solving skills</li> <li>• Depleted energy and fluctuating levels of motivation</li> </ul>	<ul style="list-style-type: none"> <li>• Streamline data requirements from claimants by sharing appropriate data and supporting evidence between benefit applications, including between PIP and UC, with the claimant's consent.</li> <li>• Pre-fill basic details for renewal and reassessment forms, such as name, address and health care contacts, so claimants only need to input anything that has changed.</li> <li>• Design online forms so people can save their progress and return at a later time and clearly communicate that this is possible to claimants.</li> <li>• Make forms (specifically PIP2 and UC50) modular, so people clearly know which sections to fill in (and which they don't need to).</li> <li>• Develop questions to assess mental health problems which go beyond generic challenges relating to coping with change and interpersonal relationships, in order to more accurately ascertain how difficulties affect people's lives on a daily basis.</li> </ul>
<b>Inaccessible appointments and communications</b>	<ul style="list-style-type: none"> <li>• Social anxiety</li> <li>• Communication problems (phone and post phobia)</li> <li>• Depleted energy and motivation</li> <li>• Increased impulsivity</li> <li>• Memory problems</li> </ul>	<ul style="list-style-type: none"> <li>• Always offer more than one choice of communication channel, including offering alternatives to post and telephone, such as email, webchat or text messages. These should be offered openly, rather than only when claimants request an adjustment.</li> <li>• Record claimants' communication needs and contact claimants and allow them to contact benefits agencies through these channels.</li> <li>• Provide copies of completed application forms.</li> <li>• Provide reminders of tasks claimants must complete and the relevant deadlines through a variety of channels.</li> <li>• Provide advanced notification of interview questions allowing claimants time to prepare their answers.</li> </ul>
<b>Relationship dynamics</b>	<ul style="list-style-type: none"> <li>• Feelings of powerlessness</li> <li>• Reduced self efficacy, shame</li> <li>• Fluctuating levels of motivation</li> <li>• Depleted energy</li> <li>• Paranoia /delusions</li> </ul>	<ul style="list-style-type: none"> <li>• Provide copies of full assessment reports with all PIP and ESA decision letters.</li> <li>• Offer video recordings of work capability and medical assessments by default.</li> <li>• Build recognition and understanding of mental health problems by training staff, including interview techniques which help people overcome memory challenges and articulate the fluctuating nature of their condition.</li> <li>• Anticipate claimants' concerns by recognising the potential distress involved in talking about mental health problems, and reinforcing that the aim of the interview is to understand a person's needs or capability for work.</li> </ul>

Source: Money and Mental Health Policy Institute

## 7.2 Acute mental illness

Principles of universal design will benefit all claimants, making it easier for people experiencing common mental health problems to have equal access to their benefit entitlements. However, at times of acute crisis or for people with severe and enduring mental illness, applying for benefits, attending work capability and medical assessments, and complying with conditionality requirements, causes significant psychological distress, and creates substantial costs in terms of other social support required.

### Make it easier for people to turn off conditionality during a mental health crisis

While there are mechanisms in place to allow claimants to be relieved of the need to comply with work search or work related activity conditions during periods of illness, these may be very difficult for a person to navigate during a mental health crisis. This can mean people are subject to inappropriate sanctions, creating financial hardship which poses a barrier to recovery.

A person claiming UC may have conditionality paused due to temporary illness for up to 14 consecutive days (though a fit note is required after the first seven days). This can only be applied twice a year,<sup>48</sup> and is unlikely to provide a sufficient period of respite for a person experiencing a mental health crisis. Work search requirements may be paused for longer if a person is unwell for longer than 14 days, or more than twice a

year, if appropriate medical evidence is provided.<sup>49</sup> It may be very difficult, however, for a person to organise and provide this evidence while they are experiencing a mental health crisis. Furthermore, in this case a claimant is not automatically excluded from work related activity.<sup>50</sup> At this point, a person may also be asked to attend a WCA. While a person who is hospitalised during a mental health crisis would be treated as automatically having limited capacity for work,<sup>51</sup> it is not clear under this guidance how a person under the care of a mental health crisis team in the community should be treated. A person in crisis is unlikely to be well enough to engage with a WCA, and could lose their entitlements as a result.

People with 'complex needs' including mental health problems could also be provided with respite from conditionality on a temporary basis through a discretionary easement, but the activation of such an easement requires an interview to discuss the person's needs.<sup>52</sup> A person in the midst of a mental health crisis might struggle to attend this interview, and thus be unable to access the easement they need.

The specific needs of people in mental health crisis, and the difficulties they may experience in financial management, have been recognised by government in their recent commitment to provide an alternative access mechanism to the breathing space debt respite scheme for people receiving NHS treatment for a mental health crisis, as an inpatient or in the community.<sup>53</sup>

48. Universal Credit Regulations 2013. (SI 2013/376). 99 (4a, 4b).

49. Universal Credit Regulations 2013. (SI 2013/376). 99 (5c).

50. DWP. Advice to decision makers. Chapter J3: Work-related requirements. J3226.

51. Universal Credit Regulations 2013. (SI 2013/376). 39(6) & Schedule 8 (2)

52. DWP. Advice to decision makers. Chapter J3: Work-related requirements. J3250 – J3256.

53. John Glen MP. House of Commons Debate 24 April 2018. Hansard: Vol 639, Col 830.



A mental health crisis specific easement could extend this protection to ensure people continue to receive their entitlements while they are too unwell to engage with the system.

There are other cases of specific needs where UC regulations specifically state that conditionality requirements must not be imposed, including:

- For six months where a person's partner dies
- For six months, if a person is receiving a course of treatment for drug or alcohol dependency
- For a minimum of three months, if a person has been a victim of domestic violence, extendable to six months if they are the main carer of a child.<sup>54</sup>

In each case, these specific easements provide clarity for decision makers, and protect people in particularly vulnerable situations for a longer period of time than is usually offered, without requiring a person to go through a WCA to change their claim status at a particularly difficult time.

### Recommendation

Universal Credit Regulations should be amended to introduce a new easement for people receiving treatment for a mental health crisis.

### Streamline Work Capability and PIP assessment and reassessment processes for claimants with severe mental illness, learning from the Health and Social Care Assessment guidelines

Assessments are among the most stressful parts of the benefits process. Changes should be made in line with our universal design recommendations above, to reduce the psychological distress assessments can cause and help more people receive the correct outcome first time around, rather than needing to challenge decisions, struggle to meet inappropriate conditionality or go without.

Action should be taken more quickly, to ensure reasonable adjustments are consistently made to assessments for people with severe mental illnesses. For this group, the current assessment process is too often an isolating, alienating and distressing experience, where people are forced to revisit their worst days and past traumas with staff who are inadequately trained, in unsuitable environments, without support. This leaves people with severe mental illness at a significant disadvantage. People may not feel able to attend appointments, in which case they are automatically considered ineligible for PIP or fit for work. Or they may attend an assessment but seriously struggle to self advocate, and end up with an inappropriate decision.

A more appropriate assessment process for this group could be designed by drawing upon parallels of the Health and Social Care Assessment guidelines, which are used to assess people with similarly high needs.<sup>55</sup>

<sup>54</sup>. Universal Credit Regulations 2013. (SI 2013/376). 98 & 99.

<sup>55</sup>. Department of Health and Social Care. Care and support statutory guidance. 2018.

For example:

- A specialist assessor with experience and knowledge of mental health
- A choice of venues for assessment which meets the claimant's needs
- Dates and times of assessments to be set in consultation with claimants, with greater flexibility for responding to fluctuation in mental health which may mean claimants are unable to participate on the day.

#### Recommendation

The government should immediately take steps to provide adjustments to assessment processes in line with guidance for Health and Social Care assessments for people with severe mental illness.

Reassessments also often cause significant distress to people with severe mental illness, forcing them to repeatedly describe traumatic experiences, which can be distressing and generate feelings of hopelessness. The process of reassessment should be streamlined for this group to reduce distress by:

- Offering assessors the option of a new, longer time period between assessments. Five years would provide a helpful halfway house between a

'lifetime award' (that exempts a person from further work capability assessment),<sup>56</sup> and the biennial time periods that currently exist for those with the most severe mental illness. Government should be appropriately ambitious about people's recovery and ability to participate in the labour market, and reducing the disability employment gap is a key focus of the current government.<sup>57</sup> However, it is equally important to be realistic about claimants' capability to engage in work and work related activity, and to reduce the disruption to claimants by repeated, unnecessary and stressful WCAs where it is not expected for the assessment to find anything new

- When reassessing people with a SMI diagnosis, assessors should use evidence from previous assessments as a baseline, and inquire about changes, rather than starting from scratch.

These adjustments should not be dependent upon a claimant or their representative requesting it. Where a person has a primary diagnosis of SMI, the DWP should automatically consider these adjustments before contracting an assessment out to an assessment provider.

#### Recommendation

The government should simplify the reassessment process for people with severe mental illnesses.

56. Centre for Health and Disability Assessments. DWP Severe Conditions Prognosis/Re-referral Guidance at WCA Face to Face Assessments and Filework. 2017.

57. House of Commons Work and Pensions Committee. Disability employment gap. Seventh report of session 2016-17. 2017.





MONEY AND  
MENTAL HEALTH  
POLICY INSTITUTE