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## The impact of the transition to Personal Independence Payment on claimants with mental health problems

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#### ABSTRACT

This paper examines the impact of major social security reform on mental health claimants by analysing the transition to Personal Independence Payment in the UK. Personal Independence Payment was introduced in April 2013, replacing Disability Living Allowance as the main non-means tested disability benefit intended to assist with the additional costs associated with disability or long-term health conditions. It is important to gain a better understanding of how people with mental health problems have experienced this reform. Twelve service users were interviewed for this gualitative research. Analysis identified three main themes: problems with the Personal Independence Payment claims process; problems conveying mental health problems during the assessment process; and positive experiences associated with the transition to Personal Independence Payment. This research demonstrates that major changes in benefit policy are challenging for people with mental health problems, particularly when delivered in a climate of austerity.

#### ARTICLE HISTORY

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#### **KEYWORDS**

Personal Independence Payment; mental health; disability benefits; welfare reform; disability policy

#### Points of interest

- The UK Government has changed the main disability benefit for disabled adults. From April 2013, Disability Living Allowance (DLA) has been phased out and replaced by Personal Independence Payment (PIP).
- This research found that this significant change caused difficulties for people with mental health problems.
- Everyone who took part reported increased anxiety, problems with claiming PIP, communicating with benefit officials and the medical assessment.

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  - It is important to learn from these problems so that future benefit changes, both in the UK and in other countries, can be developed and rolled-out in ways which are more appropriate for people with mental health problems.

#### Introduction

This paper examines the impact of social security reform on claimants with mental health problems, by analysing the transition to Personal Independence Payment (PIP) in the UK. It improves understanding about how this reform has affected this specific group of claimants. The introduction provides detail about the entitlement and rationale for PIP in a climate of austerity and discusses key criticisms. The qualitative research that informs this paper is then set out and the discussion explores how significant changes in benefit policy are challenging for people with mental health problems, especially when policy is driven by a desire to make financial savings.

#### Personal Independence Payment entitlement and rationale

Introduced in 2013, Personal Independence Payment (PIP) is the main non-means tested disability benefit in the UK, aiming to assist with the additional costs associated with disability or long-term health conditions. It replaced Disability Living Allowance (DLA), which was established in 1992. Applicants for PIP must be over sixteen and below the UK state retirement age. Since 2013, no new DLA claims have been permitted, and the Department for Work and Pensions (DWP) contacted existing DLA claimants to invite them to claim PIP. The DWP is a UK government department; it administers a range of social security benefits including PIP. The PIP claims process is lengthy, often running to several months. Payment of DLA continues during this period providing claimants submit a claim for PIP within 28 days of receiving notification from the DWP. PIP claims process but can request advice from a DWP telephone service.

A key difference between DLA and PIP is that most PIP awards are for a fixed period and subject to review, this is the case even for claimants with permanent conditions. In 2010, 71% of DLA claimants received an award of DLA for an indefinite period (DWP 2011). In contrast, between April 2013 and April 2018, 18.1% of PIP awards were for an indefinite period, with 82.8% of awards made for three and half years or less (UK Parliament 2018).

In contrast to DLA, which was criticised for relying on subjective self-assessment, PIP is a points-based system. There are two components: 'daily living' (10 activities are listed, including managing therapy or monitoring a health condition, communicating verbally, and engaging with other people face-to-face) and 'mobility' (there are two activities: planning and following journeys, and moving around). Claimants may qualify for one or both components. Each component is payable weekly at a standard or enhanced rate. A limited ability to carry out daily living or mobility activities leads to an award at the standard rate (£59.70 and £23.60 respectively for 2019/20); a severely limited ability results in an award at the enhanced rate (£89.15 and £62.25 respectively for 2019/20).

A key feature of the PIP assessment is the face-to-face consultation which requires claimants to attend a medical with an approved health professional. Official guidance indicates that medical consultations are needed when the written information that a claimant has provided is insufficient (DWP, 2018). The assessment focuses on the functional ability of claimants in relation to the activities, although the assessor may not have specialist knowledge of the claimant's condition. All applicants are permitted to have a companion present for support. Currently, PIP assessments are contracted-out to commercial third-party providers, Capita, and Independent Assessment Services (formerly ATOS Healthcare).

Disability benefit schemes across the globe vary significantly; the Organisation for Economic Co-operation and Development (OECD) (2020) statistics capture overall spending on disability and incapacity benefits and indicate that UK spending on disability benefits equates to 1.9% of GDP. This is similar to Germany (2.1%) and France (1.7%), considerably less than the Nordic Countries but higher than the United States (1.3%) and Canada (0.8%). A consideration for all countries lies in the paradox of 'much healthier populations, many more disabled people' (Niemietz 2016, 9). PIP developed in response to such changing demographics, including an ageing population and increases in mental health problems (Spicker 2017). However, it has also been heavily influenced by austerity which, since 2010, has been described as the UK's 'dominant fiscal policy' (Poinasamy 2013, 2). The Government's rationale for the introduction of PIP emphasised the need for a disability benefit 'focussed on those with greatest barriers' which enables claimants to lead full and independent lives (DWP 2012, 2). The politics of austerity underpinned this, with the desire to save money and reduce the number of disability benefit claimants; between 2003 and 2012 the number of people claiming DLA increased from 2.5 million to 3.2 million, at a cost of £12.6 billion per annum. Royston (2017, 9) fears that PIP prioritises 'reduction in provision over the effectiveness of reform' and leads to a 'shrinking disability category' (Roulstone 2015).

#### Implications for mental health in a time of austerity

A small, but growing body of literature examines the links between the implementation of PIP and mental well-being. PIP is a vital form of income

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for many disabled people. Cooper and Stewart (2015) report strong links between an adequate income and positive mental health and highlight the importance of income from social security benefits in improving choices and outcomes for adults with mental health problems. Quantitative analysis of nearly 150,000 mental health claimants and approximately 178,300 claimants with a non-psychiatric condition found that claimants transferring from DLA to PIP with a mental illness are 2.4 times more likely to have their entitlement removed than claimants with musculoskeletal conditions, neurological conditions, and diabetes (Pybus et al. 2019). Variance was reported across a range of mental health problems, with applications based on drug and alcohol use 1.97 times more likely to lose entitlement and claimants with ADHD 3.38 times more likely to lose out (Pybus et al. 2019). Official UK statistics also indicate significant issues during the DLA to PIP reassessment period with 50% of all reassessed DLA claims based on a psychiatric disorder being disallowed (Kennedy et al. 2019).

Much attention has been paid to the stigmatising effect of the UK social security system and the resulting impact on mental health (Garthwaite 2014; McNeill et al. 2017). McGrath et al. (2016) identify key features of a psychologically healthy society (agency, security, connection, meaning, trust), but argue that recent austerity policies have created an opposing set of mental health experiences (humiliation and shame, fear and distrust, instability, isolation, powerlessness). Ploetner et al. (2020) emphasise that the stigma associated with claiming benefits has a social as well as psychological dimension. An increasingly negative portrayal of benefit claimants in the media and political sphere has exacerbated this sense of stigma (Garthwaite 2011; Briant, Watson, and Philo 2013), and increased the distance between popular discourse and the lived experience (Patrick 2014, 2016).

UK austerity policies have been linked to increased suicides (Mills 2018), and receipt of social security benefits associated with higher levels of depression and anxiety (Richardson, Jansen, and Fitch 2018). UK social security policy pursued in the last decade has been found to increase financial, emotional, and psychological hardship (Clifton et al. 2013; McGrath et al. 2016). Samuel et al. (2018) highlight the breadth of reduced outcomes that are associated with inadequate income (e.g. lack of housing, personal security) and pay particular attention to the impact of social isolation and a lack of 'social connectedness'.

Given the stigma, the importance of professional advice and support for those with mental health problems has been highlighted (Moffatt, Noble, and Exley 2010; Wiggan and Talbot 2006; Barnes et al. 2017). Problems with the benefit system can be a trigger to self-harm and advice about financial issues has been found to act as a mitigating factor (Barnes et al. 2016). Given the clear links between poverty and poor mental health, it has been suggested that psychiatrists should have a working knowledge of the impact of financial hardship on patients (Fitch et al. 2007; Slade, McCrone, and Thornicroft 1995). The positive impact of welfare benefits advice can be seen on an organisational and individual level, with reduced pressure on mental health services where patients receive timely advice and support (Parsonage 2013).

#### Criticism of personal independent payment

A variety of criticisms have been levied against PIP. Allen et al. (2016) found the PIP claims process to be inaccessible for many claimants, and the assessment framework to be inconsistent and poor at recognising fluctuating conditions. Concerns have been raised that many of the daily living activities associated with the need for supervision or prompting (e.g. preparing food, managing therapy or monitoring a health condition), and which may be applicable to mental health claimants, attract a low number of points under the new assessment framework (Machin 2017).

Issues with the PIP mobility component for people with mental health problems have been equally prominent. In March 2017, the government amended the rules for the enhanced rate to exclude people experiencing mental distress when travelling independently. A challenge led to a High Court judgment that this variation was unlawful and 'blatantly discriminatory against those with mental health impairments' (RF v Secretary of State for Work and Pensions [2017] EWHC 3375 (Admin) (21 December 2017). In accepting the High Court's decision, the government committed to review all 1.6 million PIP claims made up to that point. This review process is expected to take until 2023 at a cost of £3.7bn with nearly a quarter of million claimants projected to be granted higher PIP awards (Hansard, 30 January 2018, col 703).

The appropriateness of face-to-face assessments have also been widely questioned in the press (e.g. Ryan 2019) and by policy experts (e.g. Royston 2017). Criticisms include the poor administration of the assessments, inaccessibility of some assessment centres, long waits for appointments, and intrusive questioning about personal care. Spicker (2017, 78) argues medical assessments 'either confirm the obvious or they duplicate information which is already held.' He calls for medical assessments to be the exception, with the majority of decisions based on evidence of a qualifying disability, certification from a consultant, or evidence from professionals in longstanding contact with the applicant. In addition, disability rights campaigners have questioned the appropriateness of the time-limited awards of PIP. The review process automatically commences one year before an award is due to end. It has been argued that this causes unnecessary stress for claimants, many of whom have no change in their condition, and places unwanted pressures on the public purse (Disability Rights UK 2018).

In 2014, the chair of the Public Accounts Committee labelled the implementation of PIP as 'nothing short of a fiasco' (Public Accounts Committee 2014). A review of the evidence submitted to the Committee reveals multiple concerns about the assessment of disability benefits for people with mental health problems. These include claimants being asked inappropriate questions, conditions which are not outwardly visible being disregarded and a discrepancy between the verbal account of mental health given to assessors and the written account subsequently produced (Kennedy et al. 2019). In response, the government committed to a renewed emphasis on evidence provided by health and social care professionals and consideration of how the role of companions (e.g. advocates, carers) can be strengthened (Parliament.uk 2018).

The Welfare Reform Act (2012) mandated two reviews of the effectiveness of the PIP assessment process, completed in 2014 and 2017 (Gray 2014, 2017). Both reviews expose significant issues with the assessment process for people with mental health problems, most notably that the application process is hard to navigate, and that supporting evidence is often not requested from a mental health specialist. In response, the government reiterated their belief that PIP is a significant improvement on the DLA system and committed to a cautious 'test and learn' approach. There has been international criticism of the UK disability benefits system with the United Nations (UN) Committee on the Rights of Disabled People finding that 'there is reliable evidence that the threshold of grave or systematic violations of the rights of persons with disabilities has been met' (UN 2016, 20). The UK government rejected this judgment.

Whilst there is a significant amount of research available on the UK benefits system and mental health, it is important to gain a better understanding of how people with mental health problems have experienced the transition to PIP; this paper seeks to address this gap.

#### **Research aims and method**

The overarching research question was: what is the impact of the transition from DLA to PIP on claimants with mental health problems?

Gaining insight into the lived experience of claimants was key to this study, which complements other research in this area. The importance of promoting the voices of people affected by changes to the UK social security system has been emphasised (Saffer, Nolte, and Duffy 2018; de Wolfe 2012). Beresford (2016) underscores the importance of disabled people having a genuine voice, rather than being the passive subject of the discourse. This is particularly important given that policy analysis can easily overlook a loss of 'autonomy and agency' (Sage 2018, 1047), and requires research to have a reduced focus on the medicalisation of mental health and greater emphasis

on marginalized voices (Thomas et al. 2018). The expression of marginalised voices is particularly important in the field of social security research where feelings of frustration and mistrust of bureaucracy are commonplace, and many claimants feel that their disability is viewed as invisible (Shefer et al. 2016).

Crucial to this research was its qualitative methodology, and semi-structured in-depth interviews. Marshall and Rossman (2006) highlight qualitative interviews explore participant's views and prioritise their viewpoint. Taylor and Bogdan (1998) explain that qualitative interviews can lead to an understanding of events that cannot be directly observed and semi-structured interviews allowed for some flexibility during interviews with participants while still identifying meaningful and comparable themes.

The research secured ethical approval from a University's Ethics Committee. Informed written consent was obtained from participants before the interview. Participants were also reminded that they could pause or terminate the interview at any time. Names have been changed to protect their identities.

Participants were recruited through the database of an independent social welfare advice agency; service users who had sought advice about PIP were identified. To be included, participants were required to be in receipt of DLA before they reached state retirement age, self-identifying as having mental health problems, and having experience of being migrated from DLA to PIP. The study did not seek to exclude those whose PIP claim was unsuccessful, but everyone who came forward was in receipt of PIP. Information packs containing an information sheet in plain English and consent form were posted to service users who met the inclusion criteria.

Twelve service users were interviewed: seven males and five females, all aged 35 and over. All participants were White British. A range of mental health problems were reported by participants, with depression and anxiety the most prevalent. Participant demographics, including self-identified mental health problems, are noted alongside participant quotes in the findings section.

Interviews were audio recorded and lasted between 25 min and 1 h and 10 min. Interviews took place in the participant's home or the offices of the advice agency.

Data analysis was informed by Braun and Clarke (2006)'s procedure for thematic analysis. The twelve interviews were transcribed, and the researchers familiarised themselves with the data, searched for themes, reviewed and named the themes and produced the final report. Two researchers undertook the analysis to crosscheck interpretations and to reduce potential bias in reporting.

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#### Findings

This section presents the research findings, with three overarching themes:

- 1. Problems with the Personal Independence Payment claims process
- 2. Problems conveying mental health problems during the assessment process
- 3. Positive experiences associated with the transition to Personal Independence Payment.

#### Problems with the Personal Independence Payment claims process

While each of the participants had a unique and distinctive experience of claiming PIP, a unifying theme was that the process caused increased anxiety and uncertainty. This was the case for both participants with an anxiety-related condition and participants with other mental health problems. It was striking to listen to repeated accounts of how the ambiguity that surrounds the assessment process and the scrutiny under which it places claimants worsened overall mental health:

'I was worried sick. My nerves, I suffer with my nerves anyway and I shake like anything, so yeah it has caused a lot of anxiety.' (Barbara, aged over 65, Schizophrenia)

Participants repeatedly stated that the transition to claiming PIP was an ordeal. Anxieties were reported in relation to the reduced length of PIP awards and more regular reviews, uncertainty over the eligibility criteria and points system, and concern about the potential to lose entitlement.

Notably, each of the participants expressed a clear opinion that their mental health was negatively impacted by the claims process itself, regardless of whether their PIP claim resulted in increased, reduced or identical entitlement to that experienced under DLA.

#### Poor communication with the department for work and pensions

All participants expressed disaffection in relation to communication with the DWP:

'But the communication was terrible, it doesn't sound like they are giving you a clear message about why your DLA stopped' (Mark, aged 35–44, Depression and anxiety)

'The whole experience, it was really, really, bad, considering what I have over the previous years of DLA.' (Tony, aged over 65, Schizophrenia)

This was often connected to difficulty in receiving a clear answer from DWP staff about the new criteria for PIP and when a new claim would need to be submitted:

'I also think that if they are going to send it to me, they could say in the next ... such and such a date, time, you will be getting your forms, so you would expect them to be

dropping. But now it is like this thing, hanging over your head, you know it is going to come, but you don't know when it is going to come, and you have got a fair idea it will probably go wrong, so when you are living like this anyway, that's like a big worry.' (Margaret, aged 55–64, Depression and anxiety)

Six of the research participants reported that their knowledge of PIP was based on what they could glean from the media, or from talking to family and friends rather than from official communications with the DWP.

'Most of the decent information that I got was from the internet and talking to people I know. It was good to know other people are in the same position as me and to ask them about what might happen.' (Steve, 45–54, Bipolar and personality disorder)

As Steve suggests, this sometimes proved reassuring, but it also led to mixed or false information and further anxiety. A universal concern was the lack of clear information about how the PIP points system operates (Dave, for example felt that '*The points seem ridiculous*'), and this has implications for the completion of the claim-pack which is discussed below.

Several participants welcomed the chance to speak directly with a member of staff from the DWP over the phone. Although they felt the staff treated them with respect, staff were often unable to answer specific queries. Five participants expressed concerns about the lack of clear and specific information about the medical assessment. This centred on the basics of where and when the assessment would take place, who would carry out the medical and the type of questions that would be asked.

#### Issues created by time-limited awards

Only one of the research participants was granted an indefinite award of PIP. For the remaining participants, anxieties were expressed that a process associated with uncertainty and confusion would need to be repeated in the near future:

'I am going to be jittery at the end of 2019, also towards 2020, because I know that that is the year that they will start doing the process again into 2021.' (Tony, aged over 65, Schizophrenia)

There was a clear sense of unease about the time-limited awards, often accompanied by an explanation that they were 'not going to get any better mentally' (Leanne):

'I don't agree with them putting a time-limit on it. I mean with what I have got, I am not going to get any better.' (Barbara, aged over 65, Schizophrenia)

The fear of being 'back to square one' and a lack of long-term security was reported to have negative consequences for mental health. Specific concerns centred on a lack of clarity about when a further PIP claim would need to be completed and whether a new medical would be required. This

often led to a generalised anxiety about communications with the DWP, and a fear that any correspondence or telephone call would bring unwelcome news:

'Because we had been changed, and changed, and changed. When you get a brown envelope and you know what's coming, you think 'now what's this one about?' (Linda, aged 55–64, Depression and anxiety)

'When it arrived, the brown envelope, I was shaking. Absolutely shaking and in fear it was going to say no.' (Tony, aged over 65, Schizophrenia)

'I feel very anxious about anything from the social [UK slang for the Department for Work and Pensions], it always seems to be bad news' (Leanne, aged 35–44, Depression and anxiety)

Fundamentally, there was anxiety that their time-limited awards could be discontinued when the time came for re-applying. Steve talked about feeling very worried about having to go through the whole process again in the future, explaining:

'I think they are stopping it from the wrong people, it makes me cross, and I don't trust what is going on'. (Steve, 45–54, Bipolar and personality disorder)

#### Reluctance to appeal negative decisions

A variety of decisions was issued to claimants taking part in this research. Two received higher awards of PIP compared to DLA, six saw no change in payment and four experienced a reduced award. However, all participants expressed an unease about appealing the decision:

'I don't know, I don't know whether I could have coped with it, I really don't know.' (Barbara, aged over 65, Schizophrenia)

Only one of the participants had pursued a review, known as a mandatory reconsideration, and at the time of interview was waiting for a date for an appeal tribunal. There is a two-stage appeal process. Firstly, a mandatory reconsideration must be lodged with the DWP within a month of the initial decision (section 102, Welfare Reform Act 2012). This is an internal review carried out by a DWP decision-maker not involved in the original judgment. If a claimant remains dissatisfied with this decision within a further month an appeal can be made to an independently constituted social security appeal tribunal. The tribunal is heard by a judge, medical expert and layperson with the applicant being able to present their case in person or on paper.

Participants with a reduced award expressed a reluctance to prolong the claims experience that had already caused anxiety and were justifiably concerned that a legal challenge to a benefit decision carries no protection of the initial award. Attending a tribunal was associated with 'going to court' despite the supposed informality of a hearing and the inquisitorial, rather

than adversarial, nature of the proceedings. The reality for participants was that a social security appeal tribunal is a daunting experience.

# Problems conveying mental health problems during the assessment process

Participants clearly stated that they experience significant difficulties in conveying the nature of their health problems on the claim form. The formulaic nature of the form was criticised, and doubts were expressed that it leads to an objective recording of health needs. A major theme identified was problems experienced at the medical assessment. This related to issues with the practical arrangements of medicals, concern that mental health needs were not appropriately acknowledged and recorded and a feeling that the process was demeaning.

#### Problems recording complex mental health needs on the claim form

Ten of the participants were concerned that the claim form does not facilitate the accurate recording of complex and often fluctuating mental health problems:

'The forms, you can't put as much on them, so there wasn't room for me to put what I needed to put on.' (Margaret, aged 55–64, Depression and anxiety)

Participants valued professional support to complete the application and explained that official forms in themselves cause anxiety. The format of the claim-pack was questioned, as it was felt that they encourage a tick-box response that does not reflect the intricacies of mental health problems. As participants felt that the PIP points system had not been clearly explained to them, this created uncertainty about what should be documented on the form and how this new benefit differs from DLA.

'All seems like a massive effort which isn't worth the worry for people like me, I would have given up without help and then really struggled with less money to live on.' (Dave, aged 45–54, Schizophrenia)

#### Issues with the medical assessment

A dominant theme was a discontentment with the medical assessment process, particularly when they had 'already had these medicals' (Barbara). Issues relating to poor communication about the practicalities of the medical assessment have been described above. Four participants reported that they had arrived for a medical only to be told that it had been cancelled. For claimants with mental health problems this caused significant emotional as well as practical upheaval.

These participants unanimously reported that a defensive and unhelpful stance was adopted by both Capita and the DWP when a medical was cancelled. In one instance, Capita could provide no explanation about why the medical had been cancelled despite the applicant travelling to a neighbouring city for the appointment. In another case, the DWP contacted the applicant the day after a medical was cancelled at Capita's request to ask why she had not attended:

'I had four appointments and all four were cancelled. And one actually on the morning of the appointment, and yet they phoned me the next day and asked me why I hadn't been for the appointment.' (Linda, aged 55–64, Depression and anxiety)

All but one of the participants were asked to attend a medical and each of these voiced dissatisfaction with the process. It should be noted that not all participants felt that they were treated with a lack of respect on a personal level, and one participant reported a positive encounter with the assessor:

'The woman at the medical was very nice, she went into things in detail' (Joyce, aged 55–64, Acquired brain injury)

However, a consistent objection was that the process was formulaic and 'tick-box' in nature making it difficult to accurately convey the impact of complex mental health problems. It was felt that the format of the medical led to an impersonal environment as a series of multi-choice style responses were recorded by the assessor who appeared to act merely as a data-inputter:

'She just seemed interested in this script, she was on her computer all the time, then she would look up and ask me a question and then type away.' (Margaret, aged 55–64, Depression and anxiety)

Two participants felt the assessor did not accept the extent of their mental health issues, and one participant reported that the physical tasks that they were asked to undertake were inappropriate and caused discomfort:

'She doesn't see you in pain, she just writes things down as though you are not in any pain. But you are.' (Linda, aged 55–64, Depression and anxiety)

#### Worrying about being misunderstood

A recurrent theme was that participants felt judged by the PIP assessment process and as though there was a lack of understanding about what the impact of their mental health problems could be:

'To be honest, I was just relieved when it was done, I don't know if they understood my health problems.' (Kevin, aged 45–54, Psychosis and bipolar)

'It doesn't seem right that the medical assessment is done by the same people if you have mental problems or not. I'm not sure they really got what I was trying to say to them". (Dave, aged 45–54, Schizophrenia)

For some the feeling of being judged occurred at the medical but for others confusion reigned about why a scrutiny was being placed on the receipt of disability benefits which had often been in payment for many years:

'That was another thing that it [the claims process] did to me, and I don't know if it has done it... but I started feeling like 'well why did I always have it then, so I have robbed them [the DWP] of all that' (Margaret, aged 55–64, Depression and anxiety)

Participants felt that their own account of mental health problems was not accepted or in some ways was invalidated through the reassessment process:

'It is really is, you know you go with the full intention of telling them how you are as an individual, but I really got the feeling that they thought I was lying.' (Tony, aged over 65, Schizophrenia)

'I don't understand why I needed to go to a medical, I have loads of medical records, I'm off work I'm not getting any better, so I don't know what they were trying to find out'. (Steve, 45–54, Bipolar and personality disorder)

There was a clear sense of consternation and injustice that previously mental health problems may have led to an award of benefit but that this was now open to question. For people experiencing ongoing mental problems it was particularly difficult to encounter a benefit system that, seemingly at a whim, had changed its classification of disability:

'I was made to feel like I wasn't disabled anymore' (Dennis, aged over 65, Depression and anxiety)

#### Positive experiences associated with the transition to Personal Independence Payment

It is important to recognise the positive features of the transition to PIP, identified by participants. The interviews underscored the importance of PIP as an essential form of income and the importance of access to professional support with benefit-related issues. For some, this major disability reform has been associated with the establishment of personal and professional support networks which were viewed as important for people experiencing mental health problems.

#### PIP remains an important source of additional income

All participants reported that PIP is a vital part of their overall income and assists not only with disabled-related expenditure, but in many cases with general household costs. Securing an award of PIP was seen as an important way of maintaining a reasonable standard of living.

'I do need the extra money from the disability as the other benefits I get are hardly enough to live on.' (Kevin, aged 45–54, Psychosis and bipolar)

The mobility element of PIP was described as important in maintaining contact with the outside world. The provision of appropriate transport helped with medical appointments, visiting family and friends and for shopping:

'Yeah, the mobility helps, if I need a taxi, or sometimes I use it to go up to the hospital or doctors... it gives me a free bus pass to have a carer...' (Mark, aged 35–44, Depression and anxiety)

The daily living component often contributed to securing a personal carer or purchasing specialist equipment or medication. For many, the additional income provided by PIP was a crucial way of being able to afford to pay for food and utility bills:

'A bit extra each month for my water, my heating, gas and electric, anything like that, that's what we used to use it for' (Linda, aged 55–64, Depression and anxiety)

It should be recognised that DLA also provided an important source of income to assist with general and disability-related expenditure. However, the PIP system creates a greater level of financial uncertainty than was previously the case. The participants in this research emphasised that the more regular reviews of PIP, and shorter length of awards, create anxiety for people with mental health problems. The four participants who experienced a reduction in their award stated that the loss of income has significant financial and health-related consequences.

#### Professional support is important and valued

All participants stated that professional support (from an independent welfare rights adviser) was crucial to better understand the PIP migration process and to be able to appropriately pursue a claim:

'If I'd not had the help, I don't think I would have got it' (Tony, aged over 65, Schizophrenia)

Professional support included help completing the application form, advice on the medical, assistance with gathering evidence to support a claim and advice in relation to a mandatory reconsideration. Professional support was rated as particularly important given the lack of clarity provided by the DWP and Capita staff. Participants valued guidance on the points system and support with being able to express the nature of health problems in an appropriate way on the claim-pack. Participants appreciated the input of professionals who treated them with dignity and respect, particularly when it was felt this was severely lacking in much of the contact with the DWP and Capita: 'At least they [welfare rights adviser] listen. I felt supported that someone was noticing me' (Dennis, aged over 65, Depression and anxiety)

#### The migration to PIP has led to new support networks

For some participants the review of their disability benefits has been accompanied with self-reflection of the medical and personal support that they require, and while this can be a challenging process it can lead to the establishment of new support networks. A consistent theme was that participants gained strength through adversity by being able to forge links with others in the local community who were also experiencing problems with social security benefits. This was often facilitated through social media or other online networks. The support of other PIP claimants was important for many participants and a way of discussing frustrations with the system and providing practical and emotional reassurance. This finding accords with earlier research which has stressed the importance of 'financial, emotional and practical support' (Saffer, Nolte, and Duffy 2018, 1570) from family and friends. For some participants it was affirming that although the benefits system was characterised by challenges, they were able to rely on formal and informal networks to support them with their claim and to feel that their disability was recognised:

'It [support from friends] provides a lifeline, yeah. I would be stuck without my friends. I don't go out on my own, so it is important to have other people who you trust' (Margaret, aged 55–64, Depression and anxiety)

#### Discussion

This research aimed to explore the impact of the implementation of PIP on claimants with mental health problems. It has demonstrated that a period of significant transformation of the UK disability benefits system has caused uncertainty and anxiety. This reflects the findings of a significant body of previous research (Mills 2018; Richardson, Jansen, and Fitch 2018; Clifton et al. 2013; McGrath et al. 2016). This study supports previous research which has emphasised that income from welfare benefits is vital for people with mental health problems (Cooper and Stewart 2015), but that the social security system can cause psychological distress (Wickham et al. 2020).

Policy makers and researchers should note that the income PIP provides was often used for day-to-day living expenses (such as utility bills and food), rather than the disability-related expenditure which PIP aims to provide. Any interruptions, or actual loss of payment of PIP, have a significant financial impact on claimants with mental health problems; as already noted claimants with mental health problems are more likely to lose entitlement to PIP than claimants with other health problems (Pybus et al. 2019).

Over the last decade, much emphasis has been placed on the stigma faced by benefit claimants (Garthwaite 2014; McNeill et al. 2017). Baumberg (2016, 182) makes links between benefit stigma and 'disrespect, embarrassment and shame'. The participants in this study talked about a system that did not respect their experiences of being disabled, and they felt misunderstood and judged. Participants emphasised feelings of being judged by medical assessors, and discomfort with the scrutiny of the PIP assessment process. Previous analysis has identified a similar range of psychological responses which can be associated with claiming disability benefits in the UK (Boardman 2020). Furthermore, it is clear that the participants in this research have been negatively impacted by the shifting construction of disability that has taken place over the last decade (Roulstone 2015); the recent programme of welfare reform has allowed the UK government to redraw the boundaries of how the state defines disability. In our research, this was most powerfully demonstrated when Dennis stated: 'I was made to feel like I wasn't disabled anymore'. This research has demonstrated that when analysing significant changes in disability policy the focus should not only be on financial and practical issues, but also on any changes to the classification of disability itself. This requires academic and professional scrutiny, but more importantly, underscores the need for disabled people to be meaningfully involved in policy formation. The political, legal, and practical criticism directed against PIP ultimately emanate from this inappropriate reclassification of disability.

This research highlighted the importance of social networks for PIP claimants with mental health problems, often fostered through online social media channels. Participants frequently stated they were unhappy with communications with the DWP, which left them unsure about key elements of the process. In the absence of clear official advice, assurance was often provided by other PIP claimants online. A new era of digital disability activism has been documented (Pearson and Trevisan 2015) and online peer-support on social security issues can be seen as an extension of this, although some participants emphasised that this should not be a substitute for clear official guidance.

This research supports the findings of other studies, including those which express concern about the design of PIP, the assessment process and DWP communication strategies. A PIP claim-pack, which facilitates the accurate recording of mental health problems and allows for appropriate decision-making remains elusive. The introduction of regular reviews was highlighted as a concern by many participants who feel that regular scrutiny of mental health problems is stressful and inappropriate. This accords with the research of Saffer, Nolte, and Duffy (2018) and de Wolfe (2012) that disabled benefit claimants often feel judged by the system and experience anxiety in securing and retaining entitlement.

Participants identified the PIP medical assessment as being particularly problematic, with anxieties focused on the feeling of being judged.

Participants felt that their individual circumstances were overlooked, and that the assessment was formulaic rather than person-centred. This research indicated that the emphasis on a tick-box approach is inappropriate for people with mental health problems. Previous studies have indicated that benefit medical assessments can exacerbate mental health problems and lead to an increase in suicides and the prescription of anti-depressants (Barr et al. 2016; Boardman 2020). There have been calls for medical assessments to be scrapped altogether (Pybus et al. 2021) and this would be a move universally welcomed by the participants in this study. The criticism of PIP medical assessments made by the National Audit Office (2016), and Public Accounts Committee (2014), was strongly mirrored by the views of participants in this research.

This research demonstrates the problems experienced by claimants with mental health problems because of poor communication with the DWP. Individually, there were reports of positive interactions with DWP staff, but overall participants found that both verbal and written communication was delivered in a guarded manner which inhibited their navigation of a complex system. This caused particular problems with the medical assessment, but participants also struggled to obtain clear information about how to appropriately complete the claim-pack. There have been long-standing calls for the need to improve claimant-DWP communication channels (Slade, McCrone, and Thornicroft 1995; Citizens Advice 2014).

Concern was expressed about the potential loss of entitlement to disability benefits and uncertainty about the timescales associated with the claims process. These findings are consistent with research by Shefer et al. (2016) which explored the increased anxiety experienced by mental health claimants who lost their entitlement to disability benefits. Participants reported a significantly increased anxiety related to the removal of benefit, problems with overly bureaucratic systems and frustration at the lack of awareness of 'invisible' health conditions; this reflects previous research in this area (Galloway, Boland, and Williams 2018; Elliott 2016).

In a parliamentary debate on PIP, concerns were raised about DWP staff exhibiting 'compassion fatigue' (Hansard, 26 March 2019, column 75WH) and in a case widely reported in the media, a PIP claimant was described as a 'lying bitch' in the official documents prepared by the DWP (Butler 2019). In contrast to DWP staff, participants emphasised the importance of professional advice and advocacy provided by independent welfare rights advisers. These advisers were seen as important in securing correct entitlements and to 'give voice' to their needs. This reflects a long-standing acknowledgment of the critical role provided by welfare rights advisers in helping vulnerable claimants to pursue welfare benefit claims (Wiggan and Talbot 2006; Moffatt, Noble, and Exley 2010).

This study was not just concerned with how people with mental health problems interact with the UK social security system; it also investigated the

impact of major policy transformation. This research adds to the existing literature by demonstrating that major changes in benefit policy are challenging for people with mental health problems, particularly when policy is delivered in a climate of austerity. PIP introduced fundamental changes to the assessment of disability in the UK; this study sought to privilege the viewpoints of claimants, and all research participants stated that the new points system, assessment processes and shorter-term awards created significant anxieties.

#### Limitations and future research

It is acknowledged that the participants who took part in this research were known to an advice service and may have sought assistance due to dissatisfaction with the PIP claims process. The findings, therefore, may have been shaped by the views of participants eager to express disaffection with the benefits system or the political direction of UK welfare reform.

All the participants were White British and over the age of 35. Further research focusing on the demographics of race and age would help to establish if the experiences of the participants in this research are amplified by systemic racial inequalities (Salway et al. 2020; Hill 2015) and complex transitions into adulthood (Hoolachan et al. 2017). Although not excluded from taking part, this research did not involve any claimants with mental health problems who had their award removed completely during the transition to PIP. Future research specifically with that group is needed to understand their experiences of that loss of entitlement, both in terms of how the process is managed and communicated, and the impact that outcome has on them. This is particularly important given that DLA claimants with mental health problems are more likely to lose entitlement during the transition to PIP (Pybus et al. 2019). This small-scale gualitative research focused on PIP claimants with mental health problems and, therefore, did not explore the experiences of claimants with other health conditions. Further research would be welcome to identify any differences in experience of the overall PIP claimant journey across different types of mental health problems (e.g. psychosis and anxiety-related disorders) and between claimants with physical and mental health problems.

#### **Recommendations and conclusion**

Participants in this study clearly valued PIP as an important form of income and recommended that the system would be improved with longer-term awards and clearer guidance on the completion of forms. A clear recommendation was that there should be a greater reliance on evidence provided by health professionals with knowledge of the claimant; connected to this was the view that PIP medical assessments should only be used where there is an absence of existing medical evidence. This research has demonstrated that there remains an urgent need for improvements in communication between the DWP and PIP claimants at all levels. Decision letters remain confusing for many claimants with mental health problems and until improvements are made the DWP are failing to meet basic standards of customer service and impeding timely challenges of incorrect decisions.

There are important lessons for the UK, and internationally, about the ways in which mental health is affected by welfare policy which seeks to reduce expenditure and numbers of benefit recipients. Mistaken assumptions about the reason people claim disability benefits can feed into the formulation of policy (Grover and Piggott 2010). The PIP eligibility criteria and claims process was designed to realise savings of £2.8 billion and remove entitlement for over 600.000 claimants (Office for Budget Responsibility 2019). This study has shown that the mental health of PIP claimants is negatively impacted by embracing the 'austerity paradigm' (Monaghan and Ingold 2019) and a focus on budget savings and process, rather than health needs. Wickham et al. (2020, 163) have urged other countries to be mindful of the UK's approach and 'the negative mental health impact of systematic changes to the welfare system'. This research focused on the lived experience of PIP claimants, and concerns have been expressed that UK welfare benefits policy is influenced by what can be objectively measured, rather than the human impact of policy (Monaghan and Ingold 2019).

When pursuing significant changes to the benefit system, countries should avoid a 'test and learn' approach which creates significant uncertainties for claimants with mental health problems. Instead, a careful stress testing of policy should be adopted with meaningful and timely equality impact assessments to ascertain how policy affects key claimant groups. These impact assessments must be undertaken alongside claimants with mental health problems. Participants in this study consistently highlighted problems with official communications. Clearly, this mattered on an individual level to PIP claimants, but there are broader implications about the ways in which messages about benefit changes are delivered on a corporate scale. The language and messages around reform and transformation can be overwhelming for claimants with mental health problems and there is a responsibility on benefit administrators to do all they can to provide clarity around processes and timescales. Alongside this, any country implementing significant changes to its social security system will rely on expert advice and advocacy from social welfare practitioners. The accessibility of advice services for mental health claimants is crucial during periods of benefit transformation, combined with clear legal processes to challenge defective decisions.

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#### References

- Allen, K., C. Hale, K. Seton, and J. Newton. 2016. "A Deeply Dehumanising Experience M.E./CFS Journeys through the PIP Claim Process in Scotland." https://www.actionforme. org.uk/uploads/pip-report-scotland.pdf
- Barnes, M. C., J. L. Donovan, C. Wilson, J. Chatwin, R. Davies, J. Potokar, N. Kapur, K. Hawton, R. O'Connor, and D. Gunnell. 2017. "Seeking Help in Times of Economic Hardship: Access, Experiences of Services and Unmet need." *BMC Psychiatry* 17 (1): 84. doi:10.1186/s12888-017-1235-0.
- Barnes, M. C., D. Gunnell, R. Davies, K. Hawton, N. Kapur, J. Potokar, and J. L. Donovan. 2016. "Understanding Vulnerability to Self-Harm in Times of Economic Hardship and Austerity: A Qualitative Study." *BMJ Open* 6 (2): e010131. doi:10.1136/bmjopen-2015-010131.
- Barr, B., D. Taylor-Robinson, D. Stuckler, R. Loopstra, A. Reeves, and M. Whitehead. 2016.
  " 'First, Do No Harm': Are Disability Assessments Associated with Adverse Trends in Mental Health? A Longitudinal Ecological Study." *Journal of Epidemiology and Community Health* 70 (4): 339–345. doi:10.1136/jech-2015-206209.
- Baumberg, B. 2016. "The Stigma of Claiming Benefits: A Quantitative Study." Journal of Social Policy 45 (2): 181–199. doi:10.1017/S0047279415000525.
- Beresford, P. 2016. "Presenting Welfare Reform: Poverty Porn, Telling Sad Stories or Achieving Change." *Disability & Society* 31 (3): 421–425. doi:10.1080/09687599.2016.11 73419.
- Boardman, J. 2020. "Dismantling the Social Safety Net: Social Security Reforms, Disability and Mental Health Conditions." *BJPsych Bulletin* 44 (5): 208–212. 5. doi:10.1192/bjb.2020.79.
- Braun, V., and V. Clarke. 2006. "Using Thematic Analysis in Psychology." Qualitative Research in Psychology 3 (2): 77–101. doi:10.1191/1478088706qp0630a

- Briant, E., N. Watson, and G. Philo. 2013. "Reporting Disability in the Age of Austerity: The Changing Face of Media Representation of Disability and Disabled People in the United Kingdom and the Creation of New 'Folk Devils." *Disability & Society* 28 (6): 874–889. doi:10.1080/09687599.2013.813837.
- Butler, P. 2019. DWP to Restore Disability Benefits of Woman It Called 'Lying Bitch. https:// www.theguardian.com/politics/2019/apr/12/dwp-to-restore-benefits-of-disabledwoman-it-called-lying-bitch
- Citizens Advice. 2014. One Day at a Time Examining the Cumulative Impact of Welfare Reform on Benefit Claimants in Wales. https://www.citizensadvice.org.uk/Global/Migrated\_ Documents/corporate/one-day-at-a-time--report.pdf
- Clifton, A., J. Reynolds, J. Remnant, and J. Noble. 2013. "The Age of Austerity: The Impact of Welfare Reform on People in the North East of England." *Mental Health Nursing* 33 (6): 30–32.
- Cooper, K., and K. Stewart. 2015. *Does Money in Adulthood Affect Adult Outcomes? Joseph Rowntree Foundation*. https://www.jrf.org.uk/report/does-money-adulthood-affec t-adult-outcomes
- de Wolfe, P. 2012. "Reaping the Benefits of Sickness? Long-Term Illness and the Experience of Welfare Claims." *Disability & Society* 27 (5): 617–630. doi:10.1080/09687599.2012.669 107.
- Department for Work and Pensions (DWP). 2011. Analysis of Disability Living Allowance. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\_data/file/223063/analysis\_of\_disability\_living\_allowance\_DLA\_awards.pdf
- Department for Work and Pensions (DWP). 2012. Disability Living Allowance Reform. Equality Impact Assessment May 2012.https://www.gov.uk/government/uploads/system/uploads/ attachment\_data/file/220151/eia-dla-reform-wr2011.pdf
- Department for Work and Pensions (DWP). 2018. Personal Independence Payment Handbook. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\_data/file/757816/PIP-handbook.pdf
- Disability Rights UK. 2018. Scandal of Low Percentage of Indefinite PIP Awards. https://www. disabilityrightsuk.org/news/2018/july/scandal-low-percentage-indefinite-pip-awards-0
- Elliott, I. 2016. Poverty and Mental Health: A Review to Inform the Joseph Rowntree Foundation's anti-Poverty Strategy. London: Mental Health Foundation.
- Fitch, C., R. Chaplin, C. Trend, and S. Collard. 2007. "Debt and Mental Health: The Role of Psychiatrists." *Advances in Psychiatric Treatment* 13 (3): 194–202. doi:10.1192/apt. bp.106.002527.
- Galloway, A., B. Boland, and G. Williams. 2018. "Mental Health Problems, Benefits and Tackling Discrimination." *BJPsych Bulletin* 42 (5): 200–205. doi:10.1192/bjb.2018.43.
- Garthwaite, K. 2011. "The Language of Shirkers and Scroungers?' Talking about Illness, Disability and Coalition Welfare Reform." *Disability & Society* 26 (3): 369–372. doi:10.10 80/09687599.2011.560420.
- Garthwaite, K. 2014. "Fear of the Brown Envelope: Exploring Welfare Reform with Long-Term Sickness Benefits Recipients." *Social Policy & Administration* 48 (7): 782–798. doi:10.1111/ spol.12049.
- Gray, P. 2014. An Independent Review of the Personal Independence Payment Assessment. London: HMSO. https://assets.publishing.service.gov.uk/government/uploads/system/ uploads/attachment\_data/file/387981/pip-assessment-first-independent-review.pdf
- Gray, P. 2017. The Second Independent Review of the Personal Independence Payment Assessment. London: HMSO. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\_data/file/604097/pip-assessment-second-independent-review.pdf

- 22 👄 R. MACHIN ET AL.
- Grover, C., and L. Piggott. 2010. "From Incapacity Benefit to Employment and Support Allowance: Social Sorting, Sickness and Impairment and Social Security." *Policy Studies* 31 (2): 265–282. doi:10.1080/01442870903429678
- Hill, S. 2015. "Axes of Health Inequalities and Intersectionality." In *Health Inequalities: Critical Perspectives*, edited by K. Smith, C. Bambra, and S. Hill. Oxford: 95-108. Oxford University Press.
- Hoolachan, J., K. McKee, T. Moore, and A. M. Soaita. 2017. "Generation Rent' and the Ability to 'Settle Down': Economic and Geographical Variation in Young People's Housing Transitions." *Journal of Youth Studies* 20 (1): 63–78. doi:10.1080/13676261.2016.1184241.
- Kennedy, S., R. McInnes, A. Mackley, A. Bellis, S. Brown, and S. Steele. 2019. Mental Health and the Benefits Assessment Process. https://researchbriefings.parliament.uk/ ResearchBriefing/Summary/CDP-2019-0005
- Machin, R. 2017. "Made to Measure? An Analysis of the Transition from Disability Living Allowance to Personal Independence Payment." *Journal of Social Welfare and Family Law* 39 (4): 435–453. doi:10.1080/09649069.2017.1390291.
- Marshall, C., and G. Rossman. 2006. Designing Qualitative Research. London: Sage.
- Mcgrath, L., Griffin, V., Mundy, E., Curno, T., Weerasinghe, D. and Zlotowitz, S. 2016. The Psychological Impact of Austerity: A Briefing Paper. *Educational Psychology Research and Practice*. 2 (2): 46–57. doi:10.15123/uel.885xw
- McNeill, J., L. Scullion, K. Jones, and A. Stewart. 2017. "Welfare Conditionality and Disabled People in the UK: Claimants' Perspectives." *Journal of Poverty and Social Justice* 25 (2): 177–180. doi:10.1332/175982717X14943392083755.
- Mills, C. 2018. "Dead People Don't Claim': A Psychopolitical Autopsy of UK Austerity Suicides." Critical Social Policy 38 (2): 302–322. doi:10.1177/0261018317726263.
- Moffatt, S., E. Noble, and C. Exley. 2010. "Done More for Me in a Fortnight than Anybody Done in All Me Life." *How Welfare Rights Advice Can Help People with Cancer. BMC Health Services Research* 10 (1): 259.
- Monaghan, M., and J. Ingold. 2019. "Policy Practitioners' Accounts of Evidence-Based Policy Making: The Case of Universal Credit." *Journal of Social Policy* 48 (2): 351–368. doi:10.1017/S004727941800051X.
- National Audit Office. 2016. Contracted-Out Health and Disability Assessments. https://www.nao.org.uk/report/contracted-out-health-and-disability-assessments/
- Niemietz, K. 2016. Disability Benefits. A Briefing. https://iea.org.uk/wp-content/uploads/2016/12/Briefing-Disability-benefits.pdf
- Organisation for Economic Co-operation and Development (OECD). 2020. *Public Spending on Incapacity*. https://data.oecd.org/socialexp/public-spending-on-incapacity.htm#indicator-chart
- Office for Budget Responsibility. 2019. Welfare Trends Report. https://obr.uk/docs/dlm\_uploads/Welfare\_trends\_report\_2019.pdf
- Parliament.uk. 2018. PIP and ESA Assessments: Government Response to the Committee's Seventh Report of 2017–19.https://publications.parliament.uk/pa/cm201719/cmselect/ cmworpen/986/98602.htm
- Parsonage, M. 2013. Welfare Advice for People Who Use Mental Health Services. Centre for Mental Health. https://www.centreformentalhealth.org.uk/sites/default/files/2018-09/ Welfare.pdf
- Patrick, R. 2014. "Working on Welfare: Findings from a Qualitative Longitudinal Study into the Lived Experiences of Welfare Reform in the UK." *Journal of Social Policy* 43 (4): 705–725. doi:10.1017/S0047279414000294.
- Patrick, R. 2016. "Living with and Responding to the 'Scrounger' Narrative in the UK: Exploring Everyday Strategies of Acceptance, Resistance and Deflection." *Journal of Poverty and Social Justice* 24 (3): 245–259. doi:10.1332/175982716X14721954314887.

- Pearson, C., and F. Trevisan. 2015. "Disability Activism in the New Media Ecology: Campaigning Strategies in the Digital Era." *Disability & Society* 30 (6): 924–940. doi:10 .1080/09687599.2015.1051516.
- Ploetner, C., M. Telford, K. Braekkan, K. Mullen, S. Turnbull, A. Gumley, and S. Allan. 2020. "Understanding and Improving the Experience of Claiming Social Security for Mental Health Problems in the West of Scotland: A Participatory Social Welfare Study." *Journal* of Community Psychology 48 (3): 675–692. doi:10.1002/jcop.22278.
- Poinasamy, K. 2013. The True Cost of Austerity and Inequality. UK Case Study. https:// www-cdn.oxfam.org/s3fs-public/file\_attachments/cs-true-cost-austerit y-inequality-uk-120913-en\_0.pdf
- Public Accounts Committee. 2014. Implementation of Personal Independence Payments Nothing Short of a Fiasco. https://www.parliament.uk/business/committees/ committees-a-z/commons-select/public-accounts-committee/news/personal-independenc e-payments-substantive/
- Pybus, K., K. Pickett, C. Lloyd, S. Prady, and E. Wilkinson. 2021. "Functional Assessments in the UK Social Security System: The Experiences of Claimants with Mental Health Conditions." *Journal of Social Policy* 50 (2): 305–318. doi:10.1017/S0047279420000094.
- Pybus, K., K. Pickett, S. Prady, C. Lloyd, and R. Wilkinson. 2019. "Discrediting Experiences: Outcomes of Eligibility Assessments for Claimants with Psychiatric Compared with Non-Psychiatric Conditions Transferring to Personal Independence Payments in England." *BJPsych Open* 5 (2): e19. doi:10.1192/bjo.2019.3.
- RF v Secretary of State for Work and Pensions [2017] EWHC 3375 (Admin), 21 December 2017. https://www.bailii.org/ew/cases/EWHC/Admin/2017/3375.html
- Richardson, T., M. Jansen, and C. Fitch. 2018. "Financial Difficulties in Bipolar Disorder Part 1: Longitudinal Relationships with Mental Health." *Journal of Mental Health* 27 (6): 595–601. doi:10.1080/09638237.2018.1521920.
- Roulstone, A. 2015. "Personal Independence Payments, Welfare Reform and the Shrinking Disability Category." *Disability & Society* 30 (5): 673–688. doi:10.1080/09687599.2015.10 21759.
- Royston, S. 2017. Broken Benefits. What's Gone Wrong with Welfare Reform. Bristol: Policy Press.
- Ryan, F. 2019. What I Felt When I Passed the Benefit Test. https://www.theguardian.com/ commentisfree/2019/jul/18/disability-benefit-reforms-tests-pip
- Saffer, J., L. Nolte, and S. Duffy. 2018. "Living on a Knife Edge: The Responses of People with Physical Health Conditions to Changes in Disability Benefits." *Disability & Society* 33 (10): 1555–1578. doi:10.1080/09687599.2018.1514292.
- Sage, D. 2018. "Reversing the Negative Experience of Unemployment: A Mediating Role for Social Policies?" *Social Policy & Administration* 52 (5): 1043–1059. doi:10.1111/ spol.12333.
- Salway, S., D. Holman, C. Lee, V. McGowan, Y. Ben-Shlomo, S. Saxena, and J. Nazroo. 2020. "Transforming the Health System for the UK's Multi-Ethnic Population." *BMJ* 368: m268. doi:10.1136/bmj.m268.
- Samuel, K., S. Alkire, D. Zavaleta, C. Mills, and J. Hammock. 2018. "Social Isolation and Its Relationship to Multidimensional Poverty." Oxford Development Studies 46 (1): 83–97. doi:10.1080/13600818.2017.1311852.
- Shefer, G., C. Henderson, M. Frost-Gaskin, and R. Pacitti. 2016. "Only Making Things Worse: A Qualitative Study of the Impact of Wrongly Removing Disability Benefits from People with Mental Illness." *Community Mental Health Journal* 52 (7): 834–841. doi:10.1007/ s10597-016-0012-8.
- Slade, M., P. McCrone, and G. Thornicroft. 1995. "Uptake of Welfare Benefits by Psychiatric Patients." *Psychiatric Bulletin* 19 (7): 411–413. doi:10.1192/pb.19.7.411.

Spicker, P. 2017. What's Wrong with Social Security Benefits ?Bristol: Policy Press.

- Taylor, S., and R. Bogdan. 1998. Introduction to Qualitative Research Methods: A Guidebook and Resource. Chichester: John Wiley and Sons.
- Thomas, F., L. Hansford, J. Ford, K. Wyatt, R. McCabe, and R. Byng. 2018. "Moral Narratives and Mental Health: Rethinking Understandings of Distress and Healthcare Support in Contexts of Austerity and Welfare Reform." *Palgrave Communications* 4 (1): 39. doi:10.1057/s41599-018-0091-y.
- UK Parliament. 2018. Personal Independence Payment. Question for the Department of Work and Pensions. https://questions-statements.parliament.uk/written-questions/de-tail/2018-07-17/165121
- United Nations. 2016. Committee on the Rights of Persons with Disabilities: Inquiry Concerning the United Kingdom of Great Britain and Northern Ireland Carried Out by the Committee under Article 6 of the Optional Protocol to the Convention.http://www.ohchr.org/ Documents/HRBodies/CRPD/CRPD.C.15.R.2.Rev.1-ENG.doc

Welfare Reform Act. 2012. https://www.legislation.gov.uk/ukpga/2012/5/contents/enacted

- Wickham, S., L. Bentley, T. Rose, M. Whitehead, D. Taylor-Robinson, and B. Barr. 2020. "Effects on Mental Health of a UK Welfare Reform, Universal Credit: A Longitudinal Controlled Study." *The Lancet. Public Health* 5 (3): E157–E164. doi:10.1016/ S2468-2667(20)30026-8.
- Wiggan, J., and C. Talbot. 2006. "The Benefits of Welfare Rights Advice." *The Journal of Poverty and Social Justice* 14 (3): 235–238.