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# The ‘madness’ of accessing justice: legal mobilisation, welfare benefits and empowerment

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## ABSTRACT

This article explores a paradigmatic case of legal mobilisation in the UK: successful litigation taken by *RF*, an anonymous claimant, against the Department of Work and Pensions’ cuts to disability mobility benefits for those facing ‘psychological distress’. While there is now a flourishing literature on the mobilisation of disability rights around the world, socio-legal scholarship has tended to overlook the mobilisation of law by those experiencing mental ill health or the potential contributions of adoption a social model of madness, mental distress and confusion. In developing a ‘thick description’ of the litigation process in the *RF* case, the article inductively identifies important lessons for scholars of legal consciousness and legal mobilisation. It showcases how the litigation process has both oppressive and empowering potential for those who are otherwise subject to systemic oppression by mental health and welfare benefit services. Second, it broadens the empirical literature on disability legal mobilisation which has largely overlooked the mobilisation of law by mental health service users and psychiatric survivors beyond issues related to psychiatric interventions, institutionalisation and detention.

## KEYWORDS

Access to justice; legal mobilisation; mental health; disability; welfare benefits

## Introduction

What it came down to was that these are really difficult times to be living in. Really bleak and really frightening, and it feels important that people try to make things different. And it feels important that people know that there are people trying . . . I thought, well even if we lose, actually trying is enough. Just so people know that they are seen and they are worth fighting for. Interview with claimant

Why and how do people mobilise the law even when the odds are stacked against them? In an age of austerity mobilising the law has become ever more difficult given shrinking legal opportunities and significant resource constraints on individuals and on the ‘support structures’ that can facilitate their efforts (Epp 1998). Furthermore, we know that these structural and material factors are not the only ones that matter: drivers of mobilisation behaviour can also operate at the level of social meaning (McCann 1994, Silbey 2005, Albiston and Sandefur 2013). When individuals recognise the wrongs done to them, take legal cases and their claims are resolved successfully, clients may feel

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recognised and empowered. However, socio-legal research suggests that this is not necessarily the case: legal rights interact with individual and group identity in complex ways and claiming legal protections can also undermine an individual's sense of self (Engel and Munger 2003, Albiston and Sandefur 2013, Chua and Engel 2019). As Albiston and Sandefur (2013, p. 112) suggest, we need to better understand 'the factors that contribute to empowerment and that avoid negative constructions of identity'.

This article contributes to theory development in this regard by presenting a unique but illustrative case study that helps to illuminate the (dis)empowering potential of the interaction between individuals and organisations through the legal mobilisation process. It focuses on an instance of legal mobilisation for welfare benefits for those experiencing psychological distress and can be understood as a 'hard case' for existing socio-legal theory. At the level of legal consciousness, Felstiner *et al.*'s (1980) framework outlining the cognitive process of 'naming', 'blaming' and 'claiming', i.e. recognising a harm that has been done, identifying who is responsible for it and seeking a legal remedy is a useful starting point. Existing research on the legal consciousness of, for example, welfare benefits recipients and disabled individuals has shown that negative social meanings can discourage people from taking advantage of legal protections and/or accessing support services to meet their needs (Albiston and Sandefur 2013, p. 112, Cowan 2004; Engel and Munger 2003, Soss 2002). For example, research in the U.S. context has shown that some welfare benefits recipients limit their use of services to only extremely dire circumstances because of social stigma and negative stereotypes about laziness, failures to be self-sufficient and state dependency (Seccombe *et al.* 1998; see also Kissane 2012, Bumiller 1988). In the U.K, research has shown how contested the notion of vulnerability is amongst welfare claimants, as well as the extent to which they feel 'marginalised and depersonalised' by the application process (Cowan 2004, p. 942). Given this conventional wisdom about the reluctance to mobilise rights to welfare benefits we ask the following questions: when and why do mental health services users and welfare benefits recipients mobilise the law? What happens when they do? The case study we extrapolate from impacted a large number of welfare benefits recipients and sheds important light on these issues.

In 2017, an anonymous individual known as RF brought legal action to challenge the UK Department of Work and Pension (DWP)'s discriminatory changes to a specific disability benefit. She was represented by the legal charity Public Law Project (PLP). PLP had been working with organisations concerned about the impact that changes would have on disabled individuals. The welfare benefit system that was challenged – personal independence payments (PIP) – was established to help offset some of the costs of being disabled. New guidelines introduced in March 2017 by the DWP stated that mental health claimants whose mobility is limited due to 'psychological distress' were in effect barred from gaining what is known as 'the mobility component' of the benefit which helps to cover the cost of support or modes of transport which enable individuals to be mobile. When an individual is assessed for PIP, a health professional looks at their ability to carry out a range of daily living activities and mobility activities and considers whether their health condition or disability limits the individual's ability to carry out the activities and how much help the individual needs in order to undertake them. The mobility component is important in facilitating independence and inclusion: being mobile enhances a person's ability to interact with others, gain an education, earn a living and participate in the community (Engel and

Munger 2003, Vanhala 2011, Revillard 2019). This change affected people with a range of conditions including learning disabilities, autism, schizophrenia, anxiety conditions, social phobias and early dementia (Kennedy 2018).

In its judgment on 21 December 2017 in *RF v. Secretary of State for Work and Pensions*, the High Court ruled that the regulations introducing the March 2017 changes were unlawful because they 'blatantly discriminate' against people with mental health impairments (in this case, overwhelming psychological distress) in breach of the Human Rights Act 1998.

In January 2018 the Government announced they would not appeal the decision and it was estimated that up to 220,000 people could benefit from the judgment, at a total cost of around £3.7 billion (Kennedy 2018).

The findings presented in this article contribute to three areas of socio-legal research. First, this research advances our understanding of the micro-level dynamics of the legal mobilisation process. In doing so it sheds light on how the process of accessing justice can have both empowering and oppressive functions at different stages. This builds on research that shows that the relationship between identity and law is complex and, at times, counter-intuitive (Albiston and Sandefur 2013, p. 112). Second, it also advances our theoretical understanding of legal mobilisation to protect, advance or activate disability rights. There is a rapidly growing body of research at the intersection of disability studies and socio-legal studies (Heyer and Mor 2019). However, to date this has largely overlooked mobilisation by mental health service users and psychiatric survivors. Where the literature has looked at mental health it has tended to focus on issues related to psychiatric interventions, institutionalisation and detention with little attention paid to issues such as access to health and social services and welfare benefits. Finally, this research highlights how mobilising the law can result in important policy victories even in those challenging circumstances which go beyond mobilising the law to enforce negative rights – those that ensure freedom from oppressive state interventions. The case sought to advance positive rights – those that require the government to play a role in facilitating individuals doing something they might be unable to do without state intervention.

The article is structured as follows. The first substantive section argues that the literature on disability rights mobilisation tends to overlook the role of mental health service users and psychiatric survivors. It draws on literature developing a social model of 'madness', mental distress and confusion and reviews recent research on mental health and human rights. We argue that listening to service users and psychiatric survivors themselves is crucial in understanding when and how injustices are perceived and acted upon. The second section discusses the methodological approach and data-gathering strategy. The third section presents the empirical findings and explores the micro-dynamics of legal consciousness and legal mobilisation during: a) the pre-litigation stage including how the problem was identified by the claimants and by civil society organisations; b) the preparation phase of the legal challenge and the hearing and the judgment and c) the 'legacy phase' of litigation after the case (McCann 2006). We endeavour to pay particular attention to the voice of the two original claimants in the case to better understand the experience of litigation on those at the heart of the process. The final section outlines how the insights presented here advance our understanding of legal mobilisation, legal consciousness and disability rights. It also identifies areas for future research.

## Socio-legal studies, mental health and mental distress

In the last decade, research exploring disability through the lens of socio-legal studies has flourished (Vanhala 2011, Barnes and Burke 2012, Arrington 2014, Heyer 2015a, Dorfman 2017, Heyer and Mor 2019). This body of work has explored, for instance, the gap between disability-rights on the books and in practice (Barnes and Burke 2006); the development, adoption, implementation and enforcement of disability rights at the organisational, local, national and international level (Lawson 2006, Kelemen and Vanhala 2010, Heyer 2015b, Baudot 2018, Lejeune and Ringelheim 2019); disability rights consciousness and rights activation (Vanhala 2015, Arrington 2016, Lejeune 2017, Revillard 2017); and collaboration and tensions within the disability rights movement in different jurisdictions (Vanhala 2011). Yet socio-legal scholars have largely overlooked how law interacts with mental health and mental distress and the ways in which the psychiatric consumer/user/survivor movement has engaged with law and human rights. This compounds a problem found in the world of legal practice: those who work on mental health and human rights decry the way in which international and national law on disability often neglects the situation of mental health service users, fails to appreciate the different nature of experiences and relationships to mental distress or how mental disability rights may exist on paper but not in practice. Bringing together research in socio-legal studies with research on critical disability theory and research on human rights and mental health law can therefore yield important insights on how the process of mobilising the law can ultimately help or hinder, empower or oppress mental health service users and those experiencing mental distress.

Like race, sex and gender, and impairment and disability, mental health and mental distress sit at the intersection of biology and embodiment, personal and collective identity and social experience (Tew 2012). The dominant approach to mental health and mental distress has been a biomedical one in which mental illness is assumed to exist as a disease within the biology of the body. The types of services that are offered to those experiencing mental distress, the research programmes that generate evidence for the development of treatments and social and medical understandings of the nature of 'recovery' from mental distress are dominated by this biomedical model of mental illness.

Criticisms of the biomedical model of mental health and mental distress date back at least as far as the anti-psychiatry movement in the 1960s and 1970s. Mental health has had its own history of activism which emerged largely in parallel with the wider disability movement. The social model of disability has been successful in shifting thinking about the nature of disadvantage related to disability – from an impairment-focused, tragedy or deficit account to an understanding of the material barriers to inclusion and the relational underpinnings of disadvantage and exclusion. There are ways in which the social model of disability is useful in understanding conceptualisations of mental health and mental distress but there are other ways in which this model has not been able to address some of the key issues that are seen as important by mental health activists (Tew 2012). Tew (2012) suggests that the priorities of mental health users may become lost if mental distress is understood as just another instance of impairment and that the notion of impairment itself does not capture the holistic reality or conceptual complexity of mental distress. For example, some mental health survivors and activists have begun to reinterpret distress experiences and associated behaviours – such as self-harming, hearing

voices ('auditory hallucinations') or holding on to unusual beliefs ('delusions') – as the best or only possible coping mechanisms (even though they may take on a momentum of their own) to deal with some of life's most challenging experiences such as physical, sexual or emotional trauma or harassment (Spandler *et al.* 2015, Cresswell and Spandler 2016). Tew (2012, p. 74) points out that these seemingly out-of-control coping mechanisms can also be understood as a way of 'expressing experiences and embodied memories that cannot easily be expressed in any other way'.

When understood as coping mechanisms or forms of voice and expression, the relationship between the individual and their distress is recast. This perspective complements the social model of disability by re-situating people as having some agency in relation to their distress experiences. While recognising that the nature of disadvantage and stigma is profoundly inter-personal it also acknowledges an intra-personal component: the renegotiation of one's relationship with one's distress experiences (Tew 2012). This has been captured in the idea of what Tew (2012) calls a 'socially situated model of mental distress' or under the wider conceptualisation of a social model of madness, distress and confusion.

The psychiatric survivors (also known as the consumers or service users) movement, including international organisations such as World Network of Users and Survivors of Psychiatry, and Mind Freedom International have a variety of stances and objectives that are united in their efforts to resist and transcend processes of marginalisation, stigmatisation, social coercion and oppression. In the UK context, organisations include National Survivor User Network or informal collectives such as Recovery in the Bin. Together they draw critical attention to the practices of labelling people as 'mentally ill,' the medicalisation of mental differences; the design and provision of social policy and support; the deprivation of liberty, involuntary treatment or detention and the participation of service users in programme design and implementation. These goals often implicitly draw on Foucauldian ideas about 'madness' or 'mental illness' as a social and cultural construct and the idea that any expression of irrationality may be seen as potentially subversive to the notion of modernity and the fabric of social relations (Foucault 2003). For example, the informal collective *Recovery in the Bin* introduces itself in the following way:

We are a User Led group for MH Survivors and Supporters who are fed up with the way co-opted 'recovery' is being used to discipline and control those who are trying to find a place in the world, to live as they wish, trying to deal with the very real mental distress they encounter on a daily basis. We believe in human rights and social justice! (Recovery in the Bin 2016)

A core contemporary agenda within progressive mental health activism then is to move from paternalistic responses of social control to the provision of services that are emancipatory and recognise the validity of the lived experience of mental distress or confusion and that tackle discrimination, exclusion and inequality (Dudley *et al.* 2012).

What role does and can the mobilisation of law play in these processes? A number of scholars have argued that the participation of people experiencing mental distress in legal and policy reforms relating to their lives is also 'critical to the goal of empowerment and to realising the full range of rights, but also communicates a message of inclusiveness and equity to wider society' (Dudley *et al.* 2012). Most mental health disability rights advocacy by non-

governmental organisations has focused on conducting investigations, writing reports and bringing media attention to egregious violations of human rights against people labelled with mental illness or experiencing mental distress (Perlin and É 2012). Scholarly analysis of legal decisions related to mental health and mental distress have tended to focus on legislation and related judgments exploring, challenging or legitimising imposed psychiatric interventions. For example, Minkowitz (2007) examines how the European Court of Human Rights in their 1992 judgment *Herczegfalvy v. Austria* (1992) rejected claims that non-consensual psychiatric interventions amount to torture, inhuman or degrading treatment or punishment. Other regional human rights courts have shown an increasing willingness to address mental health and mental distress issues (Perlin and É 2012). The Inter-American Commission on Human Rights heard its first mental disability rights case under the American Convention on Human Rights in 1999. In *Victor Rosario Congo v. Ecuador* (1999), the Commission took a pioneering approach in formalising the Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care (MI Principles).

While there is growing understanding of the role of courts in interpreting disability rights and mental health law in situations related to detention or non-consensual treatment, there is also an important need to understand the role of courts in addressing other important policy issues that are relevant to users of mental health services. Further, the role of the law should be explored across the multiple sites in which individuals might seek to enforce legal rights and entitlements because we have very little understanding of what the process of accessing justice is like for those who experience mental distress. This research seeks to fill these empirical gaps.

## Methodology

From a methodological perspective, we understand this case to be an unlikely case of legal mobilisation based on existing theory on legal consciousness and legal mobilisation for three main reasons. First, existing literature has documented the many pressures that identifying an injustice and taking a legal challenge places on (potential) claimants (Chen and Cummings 2012). These pressures were particularly acute in this case because the issue to be addressed concerned mental health conditions and therefore required individuals with lived experience of mental distress to bear the brunt of the pressures involved in an individualised system of accessing justice. Second, compared to many other policy sectors, the disability and mental health user communities in the UK do not tend to have one organisation that takes the lead in using legal tactics. In other words, the ‘support structure’ for legal mobilisation on issues such as the one in the RF case is relatively small. Third, the financial costs to the government in losing this case and ensuring that those individuals with mental health conditions be treated fairly were not negligible. Compared to cases where less is at stake financially, it would be expected that the government – a clear example of what Marc Galanter (1974) calls a ‘repeat player’ in the courts – would use all available tools to fight off the challenge.

The data gathering and analysis included a wide range of sources: the legal documents associated with the case including, for example, the Court’s judgment and the submitted written arguments, witness statement evidence, content media analysis and interview data from qualitative interviews with 14 respondents conducted between September and November 2018. The interviewees were in some way involved with the case, for example,



those working on the issue within the Public Law Project, those working with other civil society organisations, lawyers involved in the case either acting for the claimant or acting for the interveners as well as ‘outsiders’ working in civil society organisations who work in the disability and welfare benefits-policy space. We also had the privilege of interviewing the two original anonymous claimants which provided us with unprecedented insight into the complex and multi-layered impacts of mobilising the law on those at the heart of the case. Several approaches were made to representatives of the DWP and to counsel for the Secretary of State for Work and Pensions but we did not receive a response. Interview quotes have been anonymised. We analysed the qualitative data in an inductive manner to develop a ‘thick description’ of each stage of the litigation process to identify strategic considerations, engagement with other actors and critical junctures as well as to explore the nature of oppression and empowerment through the process of accessing justice.

## Legislative background

The Government launched a consultation in 2010 on the reform of Disability Living Allowance (DLA) (Department of Work and Pensions 2010). A stated aim of the reform was to create a more ‘dynamic benefit’ that would take account of individual circumstances and the impact of disabilities on people’s lives. The Government intended that PIP would rest on overall levels of functional impairment rather than basing assessments on a person’s condition or diagnosis. PIP helps towards some of the extra costs arising from a long-term ill-health condition or disability. It is not means-tested or subject to tax and it is payable to people who are both in and out of work. The Department for Work and Pensions (DWP) started to replace Disability Living Allowance (DLA) with Personal Independence Payment (PIP) from April 2013.

Applicants are evaluated by health workers from the private firms Atos or Capita, who forward their assessments to a DWP decision-maker – who scores applicants on ‘daily living’ and ‘mobility’ (The Social Security (Personal Independence Payment) Regulations, 2013, Part 2). Each component can be paid at one of two rates, either the standard rate or the enhanced rate. If, after an assessment, the DWP decision maker decides that an applicant’s ability to carry out the component is limited, she/he will get the standard rate. If it is severely limited, the applicant will get the enhanced rate. To get the mobility component of PIP, the applicant must have a physical or mental condition that limits her/his ability to plan/follow journeys and to move around.

Since its introduction five years ago, the PIP scheme has been subject to criticism (Jacques 2017). In 2017, a second independent review carried out by Social Security Advisory Committee chairman Paul Gray was critical of the assessment system, revealing that 65% of those who appealed against rejected PIP claims saw the decision overturned by judges (BBC News 2017). In March 2017, the DWP introduced regulations to reverse the effect of two Upper Tribunal judgments relating to the PIP eligibility criteria (*MH v. Secretary of State for Work and Pensions (PIP)* 2016; *Secretary of State for Work and Pensions v. LB (PIP)* 2016). The most significant change was to tighten the rules on access to the mobility component for people unable to undertake journeys due to ‘overwhelming psychological distress’. Disability and mental health organisations called on the



Government not to proceed with the changes. Some questioned how the changes fitted with the Government's stated commitment to 'parity of esteem' between physical and mental health issues (Kennedy 2018).

These changes are situated within a broader context in which the UK government has faced criticism on a number of different fronts for its austerity and poverty-related policies. In August 2017, an inquiry by the UN committee on the Rights of Persons with Disabilities (the committee's first ever inquiry) examined the government's progress in becoming compliant with the UN Convention on the Rights of Persons with Disabilities (UNCRPD). The report found that the UK government is failing to uphold disabled people's rights across a range of areas from education, work and housing to health, transport and social security (Butler 2016; see also Joseph Rowntree Foundation 2018). These findings were further supported by the report of Philip Alston, the UN Special Rapporteur on extreme poverty and human rights in 2019 (Office of the High Commissioner on Human Rights 2018).

## The legal case

The claimant in the case (RF) has been labelled with severe mental health impairments and experiences mental distress. RF often cannot leave her home and when she does travel, she experiences panic attacks and overwhelming distress. RF pursued a legal challenge by way of judicial review as someone who would also potentially be impacted by the new regulations.<sup>1</sup> This legal challenge needs to be understood as one part of a broader effort by civil society organisations that had been working on the injustices underlying the PIP regulations as a policy issue. These organisations had pursued different avenues to lobby for change without success and turned to the possibility of litigation as a last resort. A hearing was scheduled for early December 2017. Lawyers on behalf of RF argued that the regulations were discriminatory and violated the European Convention on Human Rights<sup>2</sup>; that the Government did not have the power to make the regulations as they fell outside the scope of the legislation upon which they rested; that they had failed to consult on the regulations and that the new changes had not been fairly presented in the consultation process.

Finding in favour of the claimant, Mostyn J. was highly critical of the consultation process saying there had been 'no hint' that the government held the view that people with psychological distress had lesser needs than others in relation to mobility. On considering the witness statements of charities working in the space, Mostyn J. concluded that none of the organisations had been made aware of the intention to distinguish overwhelming psychological distress from other mental health issues when PIP was first consulted upon and developed (Welfare Reform Act, 2012: Paragraph 24).

Importantly, Mostyn J. also found that the desire to save money was not a reasonable foundation for introducing the regulations in the first place noting that, 'plainly, if money was no object, the measure would not have been passed' (Welfare Reform Act, 2012: Paragraph 44). The claimant therefore succeeded on all three grounds of appeal: that the provisions violated Article 14 of the ECHR, they fell outside the scope (*ultra vires*) of the legislation upon which they rested and the Government's failure to consult prior to making the relevant regulations was unlawful.

## Stages of the legal process: bridging individual legal consciousness and collective legal mobilisation

This section outlines how injustices against those with lived experiences of mental distress are translated into legal grievances at the level of individuals and collective actors. Through interviews and analysis of documents we explored how the discrimination in the process of being assessed for PIP was first identified and experienced by individuals and organisations. We then explore the stages of the legal process.

### *Issue identification by collective actors*

For research participants who work in the mental health or disability sector the problems with the 2017 changes to PIP were obvious well before the regulations came into force. For example, one research participant from a DDPO noted:

We've been working on PIP - well even before when government came up with this idea of DLA [Disability Living Allowance] reform. It was always part of our campaign priorities ... We sent different briefings, we tried to mobilise some support among MPs, we did lobbying in Parliament. Obviously government wanted to push it through quickly (Interview 7, 29 November 2018).

Organisations also heard about the issues in a bottom-up way through their service-users and/or staff members who were facing this discrimination and exclusion in their own lives.

The changes were adopted by way of negative resolution in February 2017 with little parliamentary scrutiny. The way in which the legislative changes were adopted therefore meant that many research participants from disability and mental health organisations felt that there was little hope in terms of addressing issues at this stage. Likewise, even though the DWP convened development groups which included representatives of civil society organisations, there was a perceived failure to engage with welfare benefits organisations' representatives about the impact of policy changes on the ground. Groups mobilised and worked together through coalitions like the Disability Benefits Consortium but one of the challenges was trying to convey quite complex and technical information to MPs. After the legislative changes were passed, organisations tried a number of different avenues through which to raise the issue. For example, when the UN Committee on the Rights of Disabled People conducted an inquiry on compliance with the UNCRPD in the UK in 2017 DDPOs specifically raised the changes to PIP as a significant problem (Interview 7, 29 November 2018).

Throughout the pre-litigation stage PLP's existing networks played an important role in connecting them to an issue that was not at the centre of their expertise but was nonetheless related in important ways to their work on access to justice and the proper functioning of administrative systems (Interview 5, 16 November 2018). At this stage in the process, at a time where it looked as if litigation was a last resort, stakeholder organisations needed to weigh up different options and possibilities in terms of who might take a case and in what capacity, i.e. would they represent a client, act in their own name, act as a third party-intervener or provide a witness statement.

The EHRC were clear about their intention to act as interveners in the case from an early stage in view of their perception that the regulations created unfairness and violated Equality law. The issue at the heart of the case also clearly aligned with their strategic planning and corresponded with findings in their wider research. One interviewee from the organisation noted:

We had raised real concerns about the changes and the impact they would have. We had previously done a report called ‘Being Disabled in Britain’ which found that people with mental health conditions experienced some of the greatest barriers in society . . . We’d raised concerns about the proposed changes but the government went ahead with them and so the opportunity to take part in the case was one we couldn’t miss (Interview 10, November 12<sup>th</sup>, 2018).

### *Individual-level mobilisation*

The increasing mobilisation at the level of collective actors converged with a growing legal consciousness among those who experience mental distress trying, and failing, to access PIP. As such, the experiences of those most marginalised by the unlawfulness of the scheme were integrated into the legal processes at a relatively early stage in view of this raised collective consciousness. The two original claimants (who we refer to here as RF and SM as in the court documents) found their way to PLP via different routes. One claimant had seen and heard that a DDPO, Disabled People Against Cuts (DPAC), was interested in identifying those who would be affected by the changes. She noted the broader conversations she had been having about the issue before deciding to take action.

We knew that the government were bringing in these regulations that cut people with mental health problems out of the top level of PIP for mobility and it’s something we were talking about a lot, mostly in terms of despair really, like, “Oh, this is another thing the government are doing to us.” And then I heard that DPAC were looking into whether this was something that was challengeable, and I got in contact with them (Interview 8, 27 November 2018).

One research participant noted that this was exactly the right channel through which to find someone with lived experience of applying for PIP. She said: ‘People who are DPAC members are passionate about these things so it was the right audience. It was just the right cohort of people to reach’ (Interview 7, 29 November 2018). DPAC then liaised with PLP about the instances of discrimination they had heard about.

The claimant articulated what prompted her to first pursue, and then persevere with, the case despite the numerous challenges.

What it came down to was that these are really difficult times to be living in. Really bleak and really frightening, and it feels important that people try to make things different. And it feels important that people know that there are people trying, because I know for me there are times when there’s nothing I can do. There’s nothing useful I can do to make a difference to any of the really grim things that are going on. Last year happened to be a time when I could and I thought, well even if we lose, actually trying is enough. Just so people know that they are seen and they are worth fighting for (Interview 8, 27 November 2018).

The other claimant was in touch with staff at a large mental health charity in an informal manner and had been having conversations with friends and colleagues about the issue. She noted the instinctive sense of unfairness in the changes: “I was applying for PIP and had just been turned down for mobility . . . I thought the descriptor change was

completely unjust ... and I thought somebody needed to stand up to them [DWP] (Interview 2, 11 September 2018). She was also aware of the potential legal constraints noting that: ‘They had to have somebody who was affected within the first month [of the changes being introduced] and I realised that this was very current and there would be very few people. So I knew it was the right place, right time, right connections’ (Interview 2, 11 September 2018).

### *Gathering evidence*

The case involved a number of organisations in different capacities and a broad array of evidence .

The research shows that decisions about the role a civil society organisation might play in a legal case, as well as the evidence base needed for a case, can be shaped by organisational priorities and dynamics. We note that building an evidence base for this case had already been a priority for several organisations involved at early stages. For example, one research participant from Mind, a large mental health charity noted:

What was different for us with the *RF* case - well different to the majority of cases we do - is that it's something that came internally ... It was the organisation convincing the legal team it was something we wanted to do rather than the other way around. That had a number of benefits in that we already had the evidence ... our campaigners were already on board, we already had some insight of how this is going to affect people ... (Interview 6, 26 November 2018).

Mind's intervention drew on a variety of different types of evidence: case studies of the impact of the policy change on individuals who had been in contact with Mind; expert psychiatric evidence, and evidence about the history of the development of the policy and the failures in the consultation process. A research participant noted: ‘Those are the three things that we bring in an intervention: Expert evidence, individuals, some policy experience. To have all three of them in that case was pretty good’ (Interview 6, 26 November 2018).

Organisational concerns can also help to prioritise what kind of role an organisation should take. A research participant from another organisation noted:

We [Inclusion London] were initially considering intervening but then we thought, ‘What will we bring to this? What extra ...’ And because we did another intervention and we were threatened with costs, we thought that our trustees won't necessarily take it ... We just thought that we could provide evidence for witness statements (Interview 7, 29 November 2018).

At the individual level however this gathering of evidence can be taxing for claimants, especially those who experience mental distress. The claimant, further highlighting some of the personal challenges of taking on a case like this, noted:

There were things that were really difficult. I think we gave three different witness statements that were mostly about who I was and my mental health, and that's a really hard thing to talk to someone about. It's really rare that I will ever talk to anyone who doesn't have mental health problems, about my mental health ... There's something really fundamental that

people without mental health problems just don't get . . . The way law works and the way legal processes work, it was often very pressurised. Giving a statement in quite a pressurised way about something really intimate, and difficult (Interview 8, 27 November 2018).

Meanwhile the EHRC had been working on the issue of welfare reform as a strategic priority across the organisation from a policy, research and legal perspective. The legal team had pursued a number of interventions on cases concerning a number of welfare issues including the so called 'bedroom tax' and 'benefit cap'. In this case, there was a consensus that the EHRC's intervention played an important role in persuading the Court:

I think [the EHRC intervention] brought two things. One is there's a certain gravity to the EHRC intervening when your case is about discrimination. That's their role and if they get involved it shows there's a serious issue here . . . And then I think their submissions were very focused on the UN convention and that was influential with the judge . . . (Interview 5, 16 November 2018).

### *The hearing and the judgment*

Representatives from DPAC, a women-focused DDPO called Winvisible and Inclusion London attended the court and held a vigil outside (Interview 3, 1 November 2018). The importance of a claimant-led approach before, during and after the litigation is highlighted by this research:

While I was doing the case people were like, "Oh, it's such a good thing you're doing." It made me feel good. And, you know, having them show up in court was really great . . . it was just great knowing that people cared and that people wanted to support it because it's quite a lonely thing to do really, and it's quite a scary thing to do (Interview 8, 27 November 2018).

But the claimant also pointed out that support is crucial throughout the process as well as again the need to 'de-legalise' that support at different stages:

I would definitely urge anyone doing similar to get as much support as they can. A good legal team is not really enough, it wouldn't have been enough for me. Lawyers do their lawyering. I needed people who could sit through the tangled web of fear and confusion and doubt I often had. And make me cups of tea (Personal communication with research participant, 29 November 2018).

The successful outcome and the strong judgment that underpinned it was positively received by all those involved in the case who were against the legislative changes. For example, the claimant when asked about the outcome of the case responded: 'It was just amazing! We won on all grounds! I was really surprised and really happy . . .' (Interview 8, 27 November 2018).

### *The 'legacy phase'*

It is often difficult to define an endpoint to a strategic litigation process. In addition to conclusion of the costs stage of the litigation, further substantive work is often required to ensure compliance with the overall strategic objective of the case or to ensure the implementation of the judgment. This can include additional litigation, work with government

and other stakeholders to develop lawful policy, guidance or systems, training and/or communications work. Here we present our findings regarding the implementation work that was undertaken and how actors make decisions about what types of ‘legacy’ activities are necessary as a minimum in order to ensure that a court victory ‘sticks’.

Having initially said they would pursue an appeal, in January 2018 the Secretary of State for Work and Pensions instead said they would ‘take all steps necessary to implement the judgment in *MH* in the best interests of our claimants, working closely with disabled people and key stakeholders over the coming months’ (House of Commons 2018). In other words, it was suggested that they would look to develop PIP in a non-discriminatory way so that those with mental health problems could get support with mobility. The government announced that a total of 1.6 million of the main disability benefit claims will be reviewed, with around 220,000 people expected to receive more money (this number has been revised several times).

Organisations pursued a variety of different activities to encourage the government to make the relevant changes after the case. Having clear guidance for frontline workers making decisions about entitlements to benefits was an important factor in ensuring the implementation of the judgment. Justice Mostyn had expressly noted his surprise in the judgment that DWP decision makers had previously been given ‘no explicit guidance’ by the DWP for those who might be disqualified if the cause of inability to plan or follow a journey was psychological distress (House of Commons 2018: Paragraph 27).

Several non-DDPO organisations were approached directly after the government’s decision not to appeal to become involved in the developing the guidance during the implementation phase of the legal decision. The involvement of so many organisations presented challenges in terms of determining where responsibility for implementation lay and in keeping all key stakeholders informed and involved.

We were trying throughout all our comms and media stuff to talk about RF, to talk about PLP ... Then as soon as [the government decides] not to appeal and they want to work with somebody to implement the judgment DWP then comes and wants to speak to us [Mind] about it rather than PLP. So then we’re trying to make sure PLP is involved, and RF is involved and doesn’t feel like she’s won this judgment and then been excluded from the implementation (Interview 6, 26 November 2018).

The claimant’s involvement in the case therefore did not end with the handing down of the court’s judgment. In fact, several participants highlighted the importance of the claimant’s involvement in the implementation phase:

We advised RF on [commenting on the draft regulations after the case], she had her own points but we had some extra ones to add. I have to say she was a really great client for a case like this, because she was so on it and engaged. Her comments and her feedback were always really useful and informative. You really felt like you had a client who really cared about the bigger issue (Interview 5, 16 November 2018).

The potential for litigation to empower individuals and connect them to collective actors in the space continues into the implementation phase. A priority for the claimant after the decision was that DWP engage with DDPOs directly:



I engaged with drafting the guidance. And [the claimant] and Martin [claimant's QC] fed into our comments on the guidance. And I specifically and repeatedly asked for the DWP to engage with DDPOs on it ... but they basically refused and I think that that's really regrettable (Interview 3, 1 November 2018).

One research participant from a DDPO also noted their concerns about engaging with DWP.

[The claimant] wanted DWP to engage with DDPOs. We always ask DWP to do that and they never do ... They have quite a cosy circle, they call them "stakeholders", like policy officers from big charities ... In January there was this huge concern because what the DWP does is they say that they consulted with you, they cite you as their partner in designing a horrible policy, so we didn't want that ... We said, "Instead we will write a statement about what the new regulations should look like, what should happen and we will publish it." (Interview 7, 29 November 2018).

## Discussion

As socio-legal literature has documented, accessing justice is not a straightforward process and can be especially challenging for those who experience mental ill-health (Pleasence and Balmer 2007, 2009). Both claimants wrestled with the decision about whether to pursue the legal challenge or not. Research participants identified a number of different reasons for not pursuing a legal case; many of which have been previously explored in existing literature on legal mobilisation but some of which are specific to the nature of the intersection of accessing justice and mental distress.

First, a major barrier many people face in choosing whether to pursue litigation in the UK is the potential cost risk and that played an important role here. The cuts to legal aid implemented by the Legal Aid, Sentencing and Punishment of Offenders Act 2012 have adversely impacted those with mental ill health issues. One study shows that almost half of all legal problems removed from scope for legal aid were experienced by those with mental ill health (Balmer and Pleasence 2018). While this matter was 'in scope' for legal aid funding SM, one of the original claimants, was nonetheless deemed ineligible. Ultimately, SM felt she had no option but to withdraw from the litigation; an important factor in this decision was that the financial risk was too significant. While RF was deemed eligible for legal aid the challenges presented by the intensive application process are made clear. She said:

The other thing that's horrible, really horrible is applying for legal aid. That's really horrible. You have to give a stranger your bank statements for the past three months and explain anything they don't understand ... There's no one else who I would ever give my bank statement to. It's just a horrible thing to have to do. And particularly because you have to do it right at the start. You know at the start you're dealing with people you don't know (Interview 8, 27 November 2018).

A second challenge several participants identified was awareness of the potential for a protracted or unsuccessful result in the end; that 'even if you win this battle you may lose the war'. For example, one claimant said "One of my friends was putting me off on the case. He was like, 'Even if you win, if you win on every point, they [DWP] will still find a way of not meeting that [need]. They'll just change the descriptor again in a different way' (Interview 2, 11 September 2018). One of the

lawyers in the case also included this, along with long time-scales, as a key reason why litigation is challenging for individuals: ‘The first conversation [I had with potential litigants addressed the fact] that litigation is stressful and that it is difficult, and that it would take a long time ... and that there were no guarantees of the outcome’ (Interview 3, 1 November 2018). One claimant talked about how the lawyer managed her expectations regarding the outcome:

Sara [at PLP] was always pretty clear from the start that it’s hard to win a judicial review. And even if you win, it might not be a ‘good win’. For example, if we’d won on failure to consult then they could go away and consult properly and do exactly the same thing. And she really drummed that into me all the way along. So I never really expected to win. And I suppose, at that point, I did have to think “Well, why am I doing this? This is a really big thing to do when I might not win, and if I do win, it might not mean anything anyway” (Interview 8, 27 November 2018).

The literature on ‘naming, blaming and claiming’ traditionally refers to the role of family, friends, colleagues, employers and organisations as ‘agents of transformation’ in raising legal consciousness and facilitating action. In this case however, despite the wider reliance on legal processes, the role of the transformation of disputes serves to ‘de-legalise’ that very process (Felstiner *et al.* 1980). This broadens the concept of ‘agent of transformation’ as conventionally understood in the socio-legal literature which focuses on the transformation towards legal or rights consciousness and activation rather than away from it.

A third reason identified by research participants was the enormous burden of taking on a public authority in a David and Goliath-type adversarial process which carries the risk of compounding the original harm. This again demonstrates the alienating power of systems that further oppress rather than empower individuals with mental ill-health conditions. One participant noted: ‘I think it’s actually quite traumatic for people. Obviously, I think they worry that they’re going to be victimised by DWP if they fight back’. (Interview 8, 27 November 2018). Another research participant said: ‘[Litigation] compounds the wrong because the defendant’s behaviour throughout litigation is usually pretty awful, and fairly sneaky at times’ (Interview 3, 1 November 2018). One of the claimants also mentioned this dynamic: ‘There are big decisions to make and I’m the only person who could make them ... the difficult thing to get your head around really is I’m taking a government minister to court, like that’s really big, but it also sort of isn’t? I did most of it from my sofa’ (Interview 8, 27 November 2018). The court process at different levels has the potential to repeatedly reinforce a medical rather than social model of disability, further exacerbating this systemic disempowerment. As RF comments, ‘To get benefits I have to use the medical model. I have to define myself in terms of my deficit and my vulnerability’. RF explains how this risks ‘identity confusion’ because it is so at odds with her own self-understanding of her condition stressing that ‘this is a thing I struggled with all the time during the case’ (Email correspondence with claimant, 26 February 2020).

A fourth reason identified by research participants for not taking a case is that it can be an incredibly emotionally and mentally draining process. The claimants both observed this at several points over the course of the litigation process. For example, one noted: ‘When I decided to take on the case, I knew that there were certain aspects of my mental

health that would probably be impacted by it. And that felt like a fair exchange. That's a choice I made. But sometimes the way it was impacting was not expected' (Interview 8, 27 November 2018). The other said:

You've got absolutely no idea of the pressure it takes in this case, so other people who this [result] is going to affect have no idea and very little gratitude of what [we] and what other claimants in other similar situations would go through, what that sacrifice was (Interview 2, 11 September 2018).

The additional burden that litigation posed for those with mental health conditions is widely stressed by participants in the research. Here, the subjective experience of those living with mental distress again highlights the challenge of trying to embed a social model of disability within the legal process. For example, one claimant noted:

I think law is not a very mad-friendly thing. There are deadlines, everything happens around a deadline in a very high-pressured way. And that can be quite difficult. I don't think that's something that lawyers can change, I think that's just the way that law works (Interview 8, 27 November 2018).

A lawyer involved in the case also stresses how difficult it can be to pursue litigation when the very assessment processes being challenged are already so taxing for potential claimants.

My view of having done a lot of litigation is that it is such an embittering process for individuals ... I think that people should be reluctant to litigate ... And I can understand why, when they are very little or no other options, why litigation is the answer. But I definitely don't underestimate how emotionally draining it is, but also how much it drains your abilities to do anything else in your life (Interview 3, 1 November 2018).

It is clear that support for the claimant, that was led by them rather than imposed by others, was important in overcoming or mitigating some of these difficulties. The original claimants found in particular that their newly developed friendship with each other allowed them to navigate some of the challenges. One noted:

[The other original claimant] was very committed to the case ... wasn't personally involved, but wanted to support me. I had good support from my friends, but sometimes ... she was the person I wanted to talk to because she understood some of the legal stuff in a way that other people didn't (Interview 8, 27 November 2018).

These challenges are heightened in strategic public interest cases, where one or several individuals have to carry the burden of trying to address a wrong done to a much larger cohort of people. The litigation process is an unduly heavy one. One of the lawyers involved in the case noted:

I was very conscious of the fact that this is a public interest case that would impact on the people that I was speaking to [who had experienced problems with their PIP]. But who wants to take that hit as it were? Who wants to be the person to take that case and carry that burden? ... One of my feelings about this case is why did it have to be RF [who took the case]? (Interview 3, 1 November 2018).

The question posed here ('why did it have to be RF?') is one that the claimant RF frequently reflects upon demonstrating that the barriers to taking a legal challenge as an individual in a public interest case are numerous and potentially long lasting:

I often think about [how] a couple of people said they would do it if no one else would. It just makes me wonder about why I was that someone else, why I didn't say the same thing. Not that I regret it at all, but it was hugely stressful with implications, some of which just don't ever go away (Email correspondence with claimant, 26 February 2020).

## Conclusions

This research shows both the empowering and repressive potential of the legal mobilisation process for mental health service users. To some extent the access to justice and legal mobilisation literature traditionally hold in common a tendency to view individuals with mental ill health conditions and welfare benefits users as vulnerable and generally disempowered by litigation processes. Likewise, the access to justice literature has tended to focus on the early stages of legal problem resolution for individuals experiencing mental ill-health rather than courtroom challenges. The politics of austerity in the UK has led to an increase in challenges to welfare reform measures in recent years and as such provides an important evidence base on the experience of multiple actors at different stages in the mobilisation of law.

We highlight two key contributions this research makes. First, this research suggests that our understanding of the legal mobilisation process as either empowering or oppressive is flawed: by taking a process approach we can better understand that both things are true at different stages. Second, a more holistic understanding of mental distress as interpreted through the social model of disability allows us to see the potentially empowering role of litigation in a more nuanced way. A future area of study that is ripe for research is the relationship between theories of legal consciousness and the social model of madness, distress and confusion. Both approaches take the processes of cognition and resulting behaviour as the units of analysis yet have not been brought together before.

## Notes

1. Another initial claimant in the case (SM) withdrew.
2. Article 14 ECHR when read in conjunction with Article 8 and / or Article 1 of the First Protocol.

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