

research article

Seeking recognition for people with severe disabilities on benefits

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This article examines how recent welfare reform in the UK has caused systemic violence to people with severe disabilities who are reliant on state benefits. It evaluates the underpinning discourse framings and changes in welfare policies, using concepts of debility and recognition to reveal the inherent contradictions in policies targeting people on the 'wrong side of inequality'. To help contribute to a recognition of the impact of these changes, the article gives voice to six people with severe disabilities who, through their benefit stories, expose the impact of this violence. Despite these injustices, their stories reveal lives lived with great courage and resilience, and worthy of much greater recognition.

Key words benefits • severe disabilities • systemic violence • debility • recognition

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Introduction

In this article we look at systemic violence: the 'life-shattering violence caused by decisions that are made in parliamentary chambers and government offices' ([Cooper and Whyte, 2017](#): 1) with regard to people with severe disabilities who are in receipt of disability benefits in the UK. We explore how this systemic violence is intrinsic to the political and social practices of maintaining a neoliberal welfare regime, with its predisposition towards the harmful targeting of populations on the wrong side of inequality, unable to meet the demands of 'bodily capacity' required for surviving without support from the state ([Puar, 2017](#): 13). Furthermore, we aim to demonstrate how these violent practices which harm people with disabilities on benefits have become normalised: taken-for-granted, overlooked or even welcomed.

We begin by exploring the violent political practices underpinning welfare reform in the UK since the early 2000s, and the implications of the introductions of

Personal Independence Payments (PIP) and Universal Credit (UC) on people with disabilities and chronic conditions. We then evaluate the underpinning discourses used to justify these changes, such as reducing fraudulent claims and the assumption that disabilities will improve sufficiently for claimants to be able to seek work. In so doing we expose the contradictions (McGowan, 2019) at the heart of these discourses. To help deconstruct this further we draw on Jasbir Puar's (2017) concept of debility and its interconnection with disability, and Judith Butler's concept of recognition (Butler 2016).

To complement the earlier analysis of the policies and discourse framing at a structural level, we then present the findings from a small empirical study exploring the situated, social workings of this systemic violence on six people with severe disabilities. Through their stories, we make visible some of the taken-for-granted violence the participants experience, and how this has impacted on their daily lives. It is hoped that these stories will help reveal the people, their concerns and suffering, and the lived reality of these benefit practices, and thereby help contribute to creating conditions that will challenge these violent practices that have been disguised and insulated by distorted and damaging discourse framing, and that have reduced due recognition of people with severe disabilities on benefits.

Welfare reform in the UK

Official recognition of who has a disability and its severity is not fixed, but determined legally through welfare policies that govern eligibility for financial support from the state at any particular time and place. Therefore, the category of disability is open to political meddling, and contingent upon ideological persuasions and economic priorities (Stone, 1984; Roulstone, 2015).

To explain the UK context, it is helpful to turn to Epsing-Andersen's (1990) typology of late twentieth century western welfare states. The UK welfare regime can be seen as straddling liberal and social democratic ideologies (not conservative ones). More recently there has been a growing entrenchment of liberal principles, such as increased means-testing and reliance on market forces, as found in the USA and Canada. This has led to damaging changes to the processes for assessing the financial support available to people with severe disabilities and chronic conditions.

Planning for these changes can be traced to the early 1990s and the pervasive influence of the neoliberal discourses emanating from the US (Stewart, 2019). These discourses coalesced around a presentation of the problem of economic hardship as being the responsibility of the individual, and the solution to this economic hardship being found in allowing the free market to determine welfare policy, rather than severity of welfare need. Changes arguably began to be actioned in 2008, when the Department for Work and Pensions (DWP) introduced the Work Capacity Assessment (WCA) which removed the pre-existing safety net and 'psychological security' that had protected people with disabilities (Stewart, 2019: 2). The WCA was designed to limit eligibility for Employment Support Allowance (ESA) and marked an inversion of the social model of disability because, although following a non-medical assessment process, it still failed to reduce the barriers people with disabilities faced (Stewart, 2019). Exploiting the 2008 economic crisis and the supposed 'necessary' austerity measures (HM Treasury, 2010) adopted in response, the coalition conservative government radically restructured the benefit system in its Welfare Reform Act 2012. This was

compounded in 2016 by the Welfare Reform and Work Act which introduced a four-year benefit freeze. This placed a threshold income of £20,000 per year for a couple, and £13,400 for a single claimant.

For clarity of focus, we must prescind from a systematic analysis of all the benefit changes targeted at people with severe disabilities, and focus on just two key ones: Personal Independence Payments (PIP) and Universal Credit (UC). Both of these introduced conditionality (related to expectations that, if deemed fit enough, claimants should seek employment), and sanctions (the withholding of payment when conditions were breached): a pre-condition and a punishment from which people with disabilities had previously been exempt (Dwyer and Wright, 2014; Grover, 2018).

PIP was introduced to replace Disability Living Allowance (DLA) which had been designed to help offset the costs associated with living with a disability. PIP's initial roll-out led to the 'mandatory retesting of around 3 million disabled people' on the grounds of eliminating exploitative and fraudulent claims (Ryan, 2019: 26). With the introduction of PIP, the DWP wanted to reduce the number of claimants and associated costs that had existed with DLA (Rahilly, 2012). Additionally, DLA was considered self-contradictory in nature because its awards were indefinite, thereby allegedly encouraging worklessness and welfare dependency (DWP, 2011). This was addressed by subjecting people with awards to periodic review and allowing for cessation should a change of circumstance indicate a reduced level of support needs. However, despite indications to the contrary, the then Secretary for Work and Pensions claimed that PIP was in fact designed to protect the most vulnerable and provide additional support to those most in need (HC Deb 21 March 2016).

As with the changes to ESA, PIP continued the shift away from benefits as a safety net, in an attempt to distinguish between those deemed as 'deserving' claimants or 'undeserving' (Roulstone, 2015; Machin, 2017). To achieve this shift, the focus was on the functional effects of disability (that is, a person's ability to participate in daily living and mobility activities), rather than what was known about the impact of the condition, as with the more medicalised view (Gray, 2014; Machin, 2017). These awards were either 'standard' for people rated as having limited disability, or 'enhanced' for people rated as having severe disability, with many assessments proving contrary to what doctors would have assessed and recommended (UNHRC, 2019). PIP assessments were outsourced to the private firms ATOS and Capita who made huge profits on the back of these inadequate and punitive assessments. Between 2013 and 2018 two-thirds of claimants were forced to appeal the original award decision and were successful with the appeal, while ATOS and Capita continued to make millions from the contracts (Bloom, 2018).

Universal Credit (UC) was designed to simplify the benefit system and was gradually rolled out to offer an integrated benefit system for claimants both in and out of work. It was designed to address the Kafkaesque complexity of the existing system, and to eventually replace PIP (Finch et al, 2014). UC was welcomed across some stakeholder groups and political parties, despite the adverse implications for people with disabilities (Tarr and Finn, 2012). For example, the digitalisation of UC assumed that people with disabilities had competence with, and access to, the internet, and were able and well enough to meet the challenges of working online (UNHRC, 2019), never mind possessing sufficient skills in the English language and the cognitive skills to do so. Another adverse implication was the problematic transfer of the Severe Disability Premiums (SDP) that had accompanied PIP. SDP was inclusive of: Income Support,

Income related Employment and Support Allowance, Housing Benefit, and Job-seekers Allowance (JSA), and amounted to an additional £180 per month in benefits. In the initial rollout of UC, when the circumstances of people with disabilities changed and they were migrated over to UC, they lost all this additional financial support. This loss was later to be subject to legal challenges (Vanhala and Kinghan, 2019). These began with judicial review proceedings (in 2018) that found the withdrawal of SDP to be discriminatory (Vanhala and Kinghan, 2019). In defiant response, the DWP set up a 'gateway transition' for those who moved on to UC while already receiving SDPs, that offered them 'transitional protection' (covering just £80 of the original £180). Temporarily, the DWP conceded that those who had changes in circumstance from that period onwards, and who were already claiming SDP, should avoid the need to make a new claim for UC. In the meantime, the migration arrangement was deemed unlawful (Vanhala and Kinghan, 2019). While the DWP awaited a further appeal, they moved the compensation up to £120 of the £180 per month, but early in 2020, they lost a bid to overturn the two High Court rulings (Vanhala and Kinghan, 2019).

The government's benefit rhetoric was accompanied by many years of negative news about welfare benefits in the media (newspaper and broadcasting coverage). Such stories contributed to embedding anti-welfare discourses which influence public opinion partly by 'othering' claimants (Patrick, 2017a), as well as reducing the claimants' sense of their own self-worth (2017b). Whether through the tabloids' relentless assault on 'benefit cheats' or through the popular emergence of 'poverty porn' television (Jensen, 2014; Jensen and Tyler, 2015), the frames through which the public have been invited to view the lives of people on disability benefits have undoubtedly been 'politically saturated' (Butler, 2016: 1). In a recent study of the UK media's coverage of benefit fraud, Gavin (2021: 717) concluded that between the period of January 2008 to December 2017, 'scarcely a day can have gone by' without some form of media reporting on benefit fraud. Consider Daily Mail headlines such as '75% of incapacity claimants are fit to work: Tough new benefits test weeds out the workshy' (Peev, 2010), and how such coverage has coincided with rising numbers of disability hate crimes (Burnett, 2017). These sustained attacks exemplify the 'aggressively violent politics that is being orchestrated from the centre of government' towards people with disabilities as well as other benefit claimants (Burnett, 2017: 217).

Discourse framing

In the previous section we have seen how the government and the media have used 'discursive normalisation' (Butler, 2016: xix) to condition the public's complicity and compliance with the systemic violence imposed on people with severe disabilities on benefits. In this section we attempt to deconstruct some of this framing in relation to the introductions of PIP and UC. As has already been stated, the discourse framing presents the ideological position that responsibility for economic hardship lies with the individual, with its inverse implication that wealth is simply a consequence of working hard in paid employment. This discourse is ironic considering that it is an accepted fact that, in the west, at least since the 1980s, there has been a declining labour share of income. In other words, wealth from employment has been growing more slowly than wealth from capital and, therefore, there is an ever-growing acceptance that work is a decreasing factor in wealth (Piketty and Goldhammer, 2014). Additionally, as Sayer (2012: 582) argues: 'labour markets and an unequal division of labour create structural

inequalities that restrict the capabilities of many workers, frustrating efforts to improve well-being via approaches that target personal, internal capabilities'. For example, 40 per cent of UC claimants are in employment of some kind but are not paid enough to be self-reliant (Klair, 2021). Nevertheless, this discordant discourse is evident in the justification given by the DWP that welfare reform would encourage a greater uptake of employment opportunities, and thereby provide a remedy for claimants' self-imposed: 'poverty, worklessness and welfare dependency' (HM Government, 2010). Thus, the DWP conveniently ignores the fact that structural and circumstantial causes of poverty have little to do with personal responsibility and internal capabilities but are a consequence of the political and economic workings of capitalism that are set on 'maximising precariousness for some and minimising precariousness for others' (Butler, 2016: 22).

To deconstruct this discourse further, we turn to Jasbir Puar's (2017) ground-breaking book *The Right to Maim: Debility, Capacity, Disability* in which she develops an intersectional exploration of structural practices that create debility for targeted populations. For Puar (2017), debility is a form of governance over those people unable to meet 'neoliberalism's heightened demands for bodily capacity' (2017: 13). Debility is not the same as disability, but connects with it, acting to unsettle the binary of disabled/non-disabled because she argues, with neoliberalism, there is no place for even the 'adequately abled' (Puar, 2017: 15). To explicate this further, Puar (2017) draws on Lauren Berlant's (2007: 754) notion of 'slow death', the accumulated effect of 'the wearing out... and deterioration' ensuing from weakened body and mind under late capitalism. Debility causes precarity 'when social structures fail or are withdrawn' from targeted groups/populations (Butler, 2016: 642), and acts to keep those not capable enough in a perpetual state of 'ongoing suffering' (Puar, 2017: 1). This is a population excluded from acquiring 'the social, cultural and political translation to disability' that would afford them appropriate resources and recognition (Puar, 2017: xiv).

Benefit changes have created debility for severely disabled people claiming benefits, even though the discourse on these changes of helping themselves through paid employment is blatantly problematic. Even the DWP, determined to push through radical welfare reform, seems to have known this. So, the focus shifted to the supposed escalating fraudulent claims and the need to recognise when someone's health improved sufficiently to have capacity for work, that is, setting a default position that assumed that having a severe disability was either a false claim, or a temporary setback. It is difficult to argue that this failure to fully recognise the settled status of severe disability for those claiming benefits on the grounds of its (supposedly) temporary severity is anything but a contradiction in terms (McGowan, 2019). This contradiction raises serious questions concerning how, even despite the discourse framing from government and the media, it can be possible that this targeting for 'ongoing suffering' (Puar, 2017: 1) can be taken for granted, or overlooked, or accepted by large parts of society.

It is also helpful to draw on Judith Butler's (2016) investigation into such contradictory thinking in her *Frames of War: When is Life Grievable?* In it she seeks to understand public compliance with how Afghanis lives are 'framed as targets' for unequal treatment, and lives of lesser value, that is, subject to precarity. She argues that it is because they inhabit a hinterland beyond our frame of reference which protects us from feeling sorrow or outrage on their behalf. In this sense, their lives 'cannot be lost' as they are 'already lost', beyond our comprehension (Butler, 2016: xix).

Butler distinguishes two kinds of comprehension towards these lost lives, beginning with 'apprehending'. This is when we apprehend aspects of their precariousness and precarity in the existing discursive frames, and this provides the basis for seeking new frames capable of the stronger comprehension: 'recognition'. Recognition is therefore when lives are no longer lost to the hinterland but more valued and grievable, making possible the conditions for change that will reduce systemic violence.

As [Butler \(2016: vii\)](#) states, to facilitate conditions where lives are 'more equally grievable', we should seek to 'apprehend the precariousness of life through the frames available to us, and... try and install new frames that could enhance the possibility of recognition' ([Butler, 2016: 4](#)). There are several avenues for doing this. For instance, research in the UK has, in recent years, raised awareness by theorising stigma, and exploring how it 'operates as a form of governance which legitimizes the reproduction and entrenchment of inequalities and injustices' ([Tyler and Slater, 2018: 8](#); [Tyler, 2021](#)). There have also been reports such as the noteworthy United Nations inquiries ([UNCRPD, 2016](#); [UNHRC, 2019](#)), as well as legal challenges. Moving beyond redress of rights, [Puar \(2017: 16\)](#) calls for a more radical and encompassing approach which challenges the debilitating political and social practices in the global north that relegate people with disabilities, alongside other marginalised groups, to lives of enduring suffering. In this article our approach is to highlight systemic violence to people with disabilities on benefits by exploring the 'specific practical political situations and the troubles they concretely give rise to' ([Mair, 2021: x](#)). To achieve this, we have so far explored the history of political practices with accompanying discourse framing that underpin welfare changes, and now we turn to exploring the associated situated social practices and activities of concern to the people these practices target.

Methodology

The article now reports on a small empirical study that gathered benefit stories from six people with severe disabilities, in order to highlight, in their words, the systemic violence of benefit practices that have become largely accepted as 'common sense' ([Jensen and Tyler, 2015: 470](#)). It is hoped that these stories will help reveal the people, their concerns, and suffering at the cutting edge of these benefit practices. The hope is also that publicising these stories will help contribute to creating conditions that will challenge the violent practices that have been disguised and insulated by distorted and damaging discourse framing, and that have reduced due recognition of severe disability.

The study design drew on a participatory action research (PAR) orientation in terms of seeking to work in partnership with two disability charities with the aim of balancing out: 'power inequalities... [to] strengthen voice, organization and action' ([Gaventa and Cornwall, 2001: 70](#)). For instance, both charities were involved in the research design and a steering group was set up consisting of: two researchers, a research assistant, two charity representatives, and a representative from the disability community. Unfortunately, in the early stages of the study, the coronavirus pandemic struck, and both charities moved to a skeletal service, with potential participants isolated at home, and adjusting to life under lockdown and the loss of their support networks. Inevitably, plans had to adapt and commitments change. This led to only one charity continuing in the partnership and acting as a gatekeeper for potential participants. The charity advertised the study in their coffee morning events and on their social media forums which led to the recruitment of six self-selected participants.

A qualitative approach was adopted, with the data-gathering proceeding through a narrative interview method. Each participant was interviewed virtually with audio-only recording, and this was structured with the use of a retrospective narrative timeline approach (Kolar et al, 2015). This involved the participant working with the researcher to visually map their lived experience of benefit changes since 2010. This approach was chosen because it combines a narrative interview method with a visual representation (although the visual representation was only for prompting purposes and was destroyed at the end of the interview). It is particularly appropriate when working with sensitive topics as it focuses attention on chronology, while allowing for personal and broader policy issues that shape experience to emerge (Kolar et al, 2015). In this way, particular attention was paid to the participants' benefit 'stories', giving a rare voice to people with a severe disability, and helping create collective stories of how this group's experiences are shaped by systemic violence.

There can be no doubt that a major limitation with this study is the small sample size and the fact that recruitment was through just one charity that supports a wide range of disabled people who identify as having neurological conditions. That said, two participants did not have this kind of disability but heard of the study through word-of-mouth and expressed an interest in participating. Also, a concern with this study, in research ethics terms, is that people with severe disabilities are seen as very 'vulnerable' and therefore potentially open to exploitation through the research processes. We are, however, uncomfortable in thinking about this group in this way because, as Butler asks: 'In portraying people and communities who are subject to violence in systemic ways, do we do them justice, do we respect the dignity of their struggle, if we summarise them as "the vulnerable"?' (Butler, 2020: 59). We do not dismiss issues around power differentials and informed consent, and, where possible, have been mindful of these areas. For instance, processes for consent were layered and continuous until the data was transcribed and anonymised, and all participants received a copy of this article before submission to the journal, in order to give them the opportunity to further contribute. We are also aware that a journal article is not the most appropriate means of disseminating the findings to a wider audience, and, to address this, we are currently planning various dissemination formats including an art installation.

The study was designed to meet ethical guidelines (BSA, 2017), and it received university-level ethical approval for pandemic conditions in May 2020. The recordings were transcribed before being coded in order to chart and theme experiences of systemic violence (Ritchie and Spencer, 1994). The themes were then analysed through the conceptual lenses discussed earlier in this article. All participants' names were replaced by pseudonyms, and identifying features removed. The findings are divided into two parts: systemic violence in the practices and procedures of the benefit system, followed by the impact of this violence on the participants.

The findings: practices and procedures (systemic violence)

This section introduces the six participants and provides a summary of their biographies before and during their engagement with the benefit system. Three participants had sought disability benefit support all their adult lives. Ben is a young man in his mid-20s who was diagnosed with a serious condition at 15. On turning 18 he applied for DLA and then ESA, before then applying for PIP. Phil is in his late 50s and was born

with a disability. He started on Income Support and transitioned through a range of disability benefits. Yvonne is in her mid-30s and became chronically unwell over ten years ago, having just completed a postgraduate degree. Yvonne initially applied for DLA, and then PIP, and, most recently, UC.

The other three participants had their working lives halted by a serious condition or accident. Jane is in late middle-age and became chronically unwell over 20 years ago. When well, she worked in a profession with a good salary but, when she was unable to continue, her savings ran out and she sought financial support through the benefit system. Jane had initially applied for DLA before having to reapply for ESA, and then PIP. Gracie and Martha are in early middle-age and developed severe disabilities post-2010. Before illness struck, Gracie had been a probation officer, and Martha a self-employed child-minder. Initially, Gracie received full pay for six months before going down to zero pay, and then facing no choice but to apply for disability benefits. This process took ten months, and, for that period, she had no income. As a result of rent arrears, her landlord took her to court and she lost her home. It was to take Gracie four years to pay all the bills back and be provided with appropriate bungalow accommodation for her and her 14-year-old daughter. Martha finished work abruptly because she thought there may be safeguarding issues caring for children while she was experiencing memory lapses: 'A few times I found myself crossing the road without looking and thought, I can't be doing that with children.' Before her diagnosis, Martha had been off work for five months and applied to the Building Engineering Services Association (BESA) scheme for the self-employed. A year later, when Martha received her diagnosis, she tried to re-engage with the scheme, but despite them knowing the seriousness of her condition, she was told they would not give her sick pay: 'It's like £110 a week and that makes a massive difference.' She was forced to use up all her savings before applying for ESA and PIP.

Continuous change: in policies and circumstances

What is apparent, from this brief introduction to the participants and summary of their benefit history, is the continuous change in policy and procedures from the year 2000 onwards. With each change, participants had to reapply for a new benefit. Despite all the participants' health deteriorating over this period, the application process and transition onto the new benefits was far from seamless or straightforward. As Yvonne stated in relation to changes:

'I remember it quite vividly because every time there's a change [in policy], it's a real emotional upheaval. You know, you fill in about three forms, go to two assessments. It's ridiculous. So, I had applied for DLA years previously in 2006 and 2008 but finally got it in 2012 after a very extreme period of illness. That was good but it was on a lower level, so I appealed and then finally, in 2014, I received the enhanced rate. But, after that, PIP started to come in around 2016–17 and they cut me off completely in 2017 for 6 months over the transition period.'

Unfortunately, being made to reapply was not just confined to a change in policy, but also a change in the applicant's circumstances, even when their award covered the period of change and their medical prognosis indicated that improvement was unlikely. Again, as Yvonne stated:

‘For some reason every time you move house or there’s another change in your circumstances, they look at every aspect of your benefits and give you an assessment for each one. When we moved house, despite having a PIP award until 2019, they re-assessed me for PIP and ESA, and then, in 2019, when Universal Credit came in, they assessed me for that.’

For the participants that had a change in circumstances that coincided with the rolling out of UC and the legal challenges to the cutting of SDP there was evident confusion on the DWP’s part as to what claimants were entitled to. For example, for Yvonne, this led to reduced financial support, and the housing benefit side of SDP moving over to UC. When she tried to clarify what was going on, she was met with evasion.

‘I know some people have had problems with the disability premiums under UC. There had been a reduction and I got stuff knocked off and I asked for an explanation and they just sent me UC statements. It doesn’t make sense why they’ve taken this off and why they’re putting it on UC. They just try to make you jump through these hoops and then give you no explanation.’

A change in marital status can also trigger cuts to disability benefits. On Yvonne marrying, her husband had his ESA stopped, resulting in a significant loss in financial support to them as a couple.

‘Before we got married in 2016, my husband had been suffering with severe social anxiety and depression and was receiving ESA. When we got married his ESA was completely cut and he was only left with Income Support. This has meant we’re £400 a month less better off.’

For those participants who were so unwell that they had to spend longer than 28 days in hospital, their benefits were completely stopped. For instance, Gracie spent 13 weeks in hospital and had her PIP stopped, despite still having to pay her rent and bills and provide for her dependent daughter. And, because her accommodation, at that stage, had not been appropriately adapted, it was suggested that she needed 24-hour care and should be moved to an elderly residential care home. Gracie was then only 32 years old, and it would have meant her daughter being taken into care. As she said:

‘There’s no support if you’re young. There’re loads of support if you’re elderly, like Help the Aged. There’s help if you’re under 18, because there’s family support and stuff. But there’s nothing when you’re working age because that’s when you are supposed to be your healthiest.’

Indecipherable application forms and assessments

With ESA and PIP, a major hurdle for participants was the completing of the application forms. This was found to be incredibly complicated, whatever the participants’ level of education. For the three who struggled with poor motor skills, using a pen to fill out the application forms proved difficult or impossible, and they

had to find someone to write them for them. All found the questions elusive, confusing and off-putting. As Jane summarised it:

‘It’s not plain English you know, they word the forms in such a way it’s almost like they’re trying to catch you out. I mean on my PIP form there were several questions that I had to keep re-reading because I wasn’t quite sure how to answer them.’

All had sought support from specialist advisors, but only a few actually received any. Problems with getting specialist advice ranged from not knowing where to go, to encountering long waiting lists for advice appointments. Any advice available came from the voluntary sector and, in particular, the charity partnered in the study, but, as Yvonne pointed out: ‘over the last ten years they’ve become less available because of reduced funding.’

Most significantly, participants found advice from the DWP confusing, or even downright unhelpful. As Yvonne stated:

‘No one knows what they’re talking about. You get talking to someone at three o’clock and then you ring back later and get someone else. They’re completely different, and tell you opposite, contradictory stuff. No one knows what benefits work or how to work it out, and what you should or should not be getting in premiums, or whether you should or shouldn’t be on incapacity benefit. The incapacity benefit is worked out like some kind of riddle on its own. It doesn’t make sense.’

Everyone found the assessment interviews insensitive and unaccommodating to their support needs. For instance, Gracie was assessed in a location with a ramp which required her mum’s assistance to help wheel her down it, and at the bottom there were extremely heavy double doors which her mother could not negotiate without help. In the end Gracie was left in her wheelchair outside while assistance was sought. Jane had a similar experience: ‘My son had to take me because I wouldn’t have been able to get there by myself. The building, which was supposed to be accessible – it was almost impossible to get into.’ Those interviewed at home or on the phone had no say in the day/time or convenience of the assessment and faced sanctions if they were unavailable because of being unwell.

Just as with the PIP application form, participants found the interview questions confusing and aggressive, and as if they were deliberately designed to wrong-foot them. Jane summed experiences up when she described it as like an interrogation:

‘I was basically in there for an hour and a half being interrogated – like a police interrogation – I spent 20 minutes of the interview crying at the questions I was being asked.’

Martha found that the questions took no account of her medical condition and cognitive problems.

‘I was asked, if you’re going to the doctor’s, how far is it to the doctor? But the issue for me isn’t the walking, it’s the finding it. So, I said, it’s

about 2 minutes and she said, I think you need to think again, I know where you live and it's not 2 minutes. So, I say, maybe it's five minutes and she replies, well is it 2 or 5? Then I said, the point is it's not far and I can walk it, and I'm not claiming I can't walk. She replies, I'm asking the questions and I think you need to think again and I'm giving you one last chance, is it 2 or is it 5? So, I ended up saying, ok it's 5 and she replied, you originally said 2! By then it was getting me upset, and I thought "I must be lying and as if it matters!" I said "You've got me really confused and I've a serious illness!" – Trying to pick holes where there's none – it wasn't like I was trying to be dishonest. I was just confused and intimidated.'

Participants were concerned that someone without a medical qualification was assessing their capabilities. As Jane commented: 'The person that did my "medical", and I use that in inverted commas because they weren't a medical professional at all'. For instance, one assessor disclosed that they were a dental hygienist. With three participants their medical conditions were too complex for the assessors to grasp or else were unknown to them, making them dismissive or unaccommodating in the type of questions asked and their evaluation of the implications of these conditions. All the participants felt that there was no consideration of fluctuations in terms of some days being better than others, and also no consideration that, for three of them, their conditions were degenerative and life-limiting. As Ben found: 'I was naïve and didn't explain how up-and-down my condition is.' Unfortunately, this was to impact on the level of award he was initially offered. As part of the paperwork for the applications the majority of participants had contacted their consultants to ask for letters of support confirming the seriousness of their conditions and inability to work. When Martha was rejected for ESA she rang her neuro-consultant and he expressed outrage at her treatment, saying: 'You've got enough stress after brain surgery and it's just ridiculous what you're being put through.'

Participants waited at least six weeks for a decision letter to arrive and they all, at some stage, appealed an award decision. For example, Gracie was refused ESA, despite not being able to wash herself properly, or put on her socks and knickers. It took her six months to get a court date to go to the tribunal. When she eventually got to court, she 'hadn't even got in the doorway before being handed a piece of paper that said I'd won my case'. Jane was told her benefits were being cut and it then took her 39 weeks to get a court date for the appeal. Ben was put on a low rate of PIP and it took him three years to gather the energy and confidence to appeal this:

'I think maybe I wouldn't have even challenged it [PIP appeal], if I was on my own. Mum was kind of pushing me to do it, and nagging me to do it. But it was definitely the right thing to do. When I wasn't getting the higher rate, it was a feeling of like, kind of, not resentment, but like unfairness.'

Findings: impact of systemic violence on participants

All the participants felt the welfare changes had negatively affected them economically, psychologically and physically. They also felt that they were treated by the benefit

system, media and wider public as fraudsters. This was seen as encouraging a lack of recognition of them as people, managing life as best as they could given their challenging health problems.

Economic hardship

All the participants experienced economic hardship on a day-to-day level that impacted on the quality of their lives. As Yvonne stated: 'You can't afford anything. You get in debt. Constant debt and there's no way out because you don't get paid enough to live on.'

When applying, or re-applying, or having payments halted and then appealing an award decision, participants reported having to use up all their savings, and being literally unable to put food on the table, never mind cover bills and rent. For instance, Phil found himself living on just £100 JSA per week for 15 months while he waited to be awarded PIP. This led to him losing his flat and not eating meals. As a consequence, his diabetes became unstable. When Gracie was refused ESA she said:

'[I was forced to] use food banks and borrow from friends and family. I used every penny of my savings. Opened up credit cards, overdrafts, loans, anything I could do to just to be able to feed me and my daughter at the time.'

Anxiety and depression

Inevitably, the benefits processes and resultant economic hardship impacted on the wellbeing of participants, reducing confidence, and causing anxiety, stress, lack of sleep, anger, and even suicidal thoughts. This was at the same time as participants were having to deal with really serious health issues, that were worsened by the stress. Three participants mentioned having symptoms of post-traumatic stress syndrome (PTSS) every time a brown envelope dropped through the letterbox, in case it came from the DWP. Jane summed all these feelings up:

'I spent so long crying and being really anxious. I developed anxiety. It was a horrible, horrible process... You know if a brown envelope comes through the post now, I get an immediate sort of panicky reaction thinking "Here we go!"... It's just too stressful for me. You feel victimised.'

Participants also reported being made to feel they were making a fraudulent claim, as though they were lying and not entitled to the benefit.

'You've gone from independent to needing to make a claim, and they made you feel fraudulent – as though I wasn't entitled and I was trying to blag my way into getting something off them... I found it really draining because I was trying to concentrate and it felt like she thought I was lying. It took me ages to accept that I'm disabled – that's bad enough – but to then be questioned when there's medical evidence that you've got [this condition]... I don't think you should have to fight for getting benefits when you're not able to work.' (Martha)

Being unrecognised

Participants felt the full force of disapproving comments by politicians and the media for them engaging with the benefit system. As Yvonne summarised it:

‘It’s the Kafkaesque nightmare of trying to apply for something... I mean the government, the media, the people who let these ridiculous stereotypes continue. It’s always easy to bully people who you perceive to be lesser than you... You just feel worthless. I think worthless is the word really. That’s how they make you feel. Completely worthless.’

Participants felt particular hostility when contacting the DWP. As Yvonne argued: ‘No one chooses to become ill – it’s beyond your control... And then being forced to engage with this system that actively hates you and that doesn’t want you to exist.’ Martha described it as being seen: ‘like a scumbag... like you’re nothing. Like you’re the dregs of society.’

Participants also reported feeling hostility from the public, neighbours, friends and family especially if, by some remote chance, they managed to participate in civil society. This is summed up by Gracie:

‘You feel like you are constantly being, like, people are looking at you as if to say, oh well she’s on benefits, isn’t she? – Why is she having a day out, you shouldn’t be having a day out, you should be inside. You’re sick, aren’t you? Stuff like that, and even like family and friends don’t understand, you’ll get it from them as well.’

Discussion and conclusion

Earlier in this article we demonstrated the contradictions behind the welfare policy changes that have led to people with severe disabilities being assessed and re-assessed for benefits on the grounds of fraudulent claims or health improvements sufficient for work. Through the participants’ stories, the debilitating social practices associated with these changes, and the impact they have had on participants’ lives, are revealed. These practices have acted to subsume severe disability claimants into debilitating practices targeted at benefit claimants more generally and have therefore blocked them from acquisition of any official recognition of the severity of their disability as a settled or deteriorating state. This unsettled recognition has been maintained by the continuous process of assessment and re-assessment and appeal that has failed to fully grasp the complexity and implications of the associated social, economic and health issues. This is despite each participant reporting a chronic and/or degenerative condition, deemed by their medical consultant to be too serious or degenerative for them to work, and too debilitating for them to have to put up with ‘ridiculous’ repeated benefit practices. Yet, despite this, each was forced to engage in these practices that, in the end, led the DWP to the same conclusion as their medical consultants, that is, that they did not have capacity to work – except, with the DWP, this continued to be seen as potentially only a temporary state.

Additionally, this unsettled recognition was facilitated by the DWP having appropriated aspects of the non-medicalised approach to disability as advanced by the social model of disability. Specialist medical perspectives were absent for the assessment

interview, thereby undermining appreciation of the severity of the participants' disability as being beyond doubt. Also, as Puar argues in relation to the medical industry in the USA, this purgatorial status has become an opportunity for them as 'nonproductive excess' (Puar, 2017: 13) to be accessed by market profiteers, as is evidenced through the outsourcing of ongoing benefit assessments to the private firms ATOS and Capita.

As well as there being no doubt that, at least for these six participants, these practices could not be justified on the grounds of fraudulent claims and/or getting them back to work, this is equally true on any grounds of saving money because, according to a report by the Office for Budget Responsibility, spending on PIP in 2018–19 was '£4.2 billion higher' than was originally estimated. Furthermore, the report concludes that it would have been a saving to have retained the DLA and not to have introduced PIP (OBR, 2019: 12). Additional costs have also ensued from the appeal processes for PIP and ESA. For instance, in 2018–19 appeals cost £61 million, which is £44 million more than they had cost in the two previous years (Bulman, 2020). Not only this, but, in the same time period, over 70 per cent of appeals in tribunals were overturned in the claimants' favour, as had been the case for the six participants, thereby demonstrating the poor quality of the original assessments and the waste of money involved (Bulman, 2020).

From the participants' stories we also see the underbelly of the sustained strategies by both government and the media to facilitate compliance with systemic violence, through the impact on the participants of framing within 'ordinary discourse' and practices of 'discursive normalisation' (Butler, 2016: xvii). For instance, participants experienced these practices as 'victimisation' and 'bullying' and 'unfair'. They felt themselves to be labelled as 'fraudulent', 'worthless', 'scumbags', and to be viewed as 'hated' and undeserving of participation in society, sadly not only by the DWP and the media, but, also, by some neighbours and family.

We hear, through participants' voices, the impact of the foundation-shaking reduced financial support (at best hindering their potential to participate in civil society, and at worst leaving them homeless and hungry). We learn how they were made to surrender to this violence through the endless humiliations and time-consuming procedures exemplified in indecipherable application forms, interrogative non-medical assessment interviews, lack of advice on or proper explanation of changes, and the need to appeal badly-assessed decisions.

This was facilitated by the relentless DWP machinery, oiled by a hostile army of bureaucrats whose default settings appeared to be 'interrogation' and 'misinformation'. This is supported by findings from the United Nations who also found bureaucratic processes in the UK designed to humiliate and undermine people claiming disability benefits (UNCRPD, 2016; UNHRC, 2019). For the participants, these bureaucrats seemed oblivious to their support needs... and inevitably so, for they were oblivious to their shared humanity. This is maybe not surprising because as Puar (2017: 13) argues, with debility 'bodies figure not as identities or subjects but as data'. We also hear the pain resulting from blows to body and mind, with increased anxiety and distress affecting their general health and contributing further to their 'slow death'. It is true that the participants, although scathed, have so far survived these onslaughts. Yet we should note that not all people with severe disabilities do, as is evidenced by the National Audit Office (NAO) who, since 2014–15, found that the DWP had investigated 69 suicides of people with disabilities struggling with their benefit claims. That's 69 out of an unknown actual number (NAO, 2020).

What this study contributes (albeit on a limited scale) is insight into how people with severe disabilities experience and reflect on political and social practices that are debilitating and violent and that have become normalised. Severely disabled benefits claimants are increasingly equated with others claiming benefits, and this merging is inevitably damaging to recognition of the true nature of their disabilities. Equally, other claimants are increasingly crippled by the debilitating and violent practices in the benefit system more broadly. The distinction between the two is ever more blurred and indecipherable. In this way, these benefit stories endorse what Puar (2017: 16) observes is happening in the global north in relation to people on the wrong-side of social inequality, that is, that they are becoming subject to ‘conditions that make disability endemic as opposed to exceptional... ones of entrenched economic, racial and social disenfranchisement’. In this way, systemic violence is indisputably exposed as intersectional and cross-cutting for populations subject to social inequality (Puar, 2017).

Despite the violent political and social practices reported by participants, what also emerges in the stories are qualities demonstrated by the participants, that dispute the discourse framing that makes them feel ‘completely worthless’. Notwithstanding the misfortune of being not only severely disabled but also – and resultantly – targeted for systemic violence, the participants embodied lives lived with great courage and resilience. They do not speak in these terms, but – by hearing their benefit stories, ‘something exceeds the frame that troubles our sense of reality’ (Butler, 2016: 9). How can we not be troubled and see the contradictions in the current practices when we contrast them with the authentic lived experience which the participants recount? We must allow ourselves to make this contrast, because it is this troubled sense of incipient contradictions (McGowan, 2019) that can lead us to come alongside this targeted group, and, wherever possible, contribute to creating conditions that will challenge these violent practices that have been disguised and insulated by distorted and damaging discourse framing, and that have reduced due recognition of people with severe disabilities on benefits.

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Conflict of interest

The authors declare that there is no conflict of interest.

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