
(doi: 10.1332/174426421X16146990181049)

This is the author's version of the work. It is posted here for your personal use. You are advised to consult the published version if you wish to cite from it: https://doi.org/10.1332/174426421X16146990181049

Copyright © 2021 Policy Press.

http://eprints.gla.ac.uk/235806/

Deposited on: 03 March 2021
Evidence, objectivity and welfare reform: a qualitative study of disability benefit assessments

Abstract

Background: Anti-welfare narratives depict welfare systems as overly-permissive, open to fraud, and fundamentally unfair. Countering these supposed ills have been political appeals to evidence and reforms made to disability benefit assessments under the banner of objectivity. But objectivity is a complex construct, which entails philosophical and political choices that tend to oppress, exclude and symbolically disqualify alternative perspectives.

Aims and objectives: To examine reforms made to UK disability benefits assessments in the name of objectivity.

Methods: Thematic analysis of 50 in-depth qualitative interviews with UK disability benefit claimants.

Findings: Reforms made in pursuit of procedural objectivity reproduce existing social order, meaning claimants without personal, social and economic resources are less likely to succeed. Data reveal an increasingly detached and impersonal assessment process, set against a broader welfare landscape in which advocacy and support have been retrenched. In this context, attaining a valid and reliable assessment was, for many, contingent upon personal, social and economic resources.

Discussion and conclusion:

Political appeals to evidence helped establish an impetus and a legitimising logic for welfare reform. Procedural objectivity offers superficially plausible, but ultimately specious, remedies to long-standing anti-welfare tropes. Despite connotations of methodological neutrality, procedural objectivity is not a politically neutral epistemological standpoint. To know disability in a genuinely valid and reliable way, knowledge-making practices must respect dignity and proactively counter exclusory social order. These latter principles promise outcomes that are more trustworthy by virtue of their being more just.

Key words: disability; welfare; objectivity; inequality
Background

This paper examines reforms to disability benefit assessments, and in doing so, acts as a window onto the political and policy nexus between evidence, welfare reform and disability. In policy terms, we consider how the topic of evidence came to be politicised and mobilised in service of retrenchment-oriented reforms to disability benefits. In practice terms, we examine the consequences of reformed disability assessments, both for claimants undergoing benefit claims, and also in relation to the trustworthiness of these knowledge-making practices.

UK welfare for disabled people involves income-replacement benefits and extra-costs benefits. Income-replacement benefits are paid through either employment and support allowance (ESA) or universal credit (UC). ESA was first introduced in 2008, replacing incapacity benefit (IB), and has since been superseded for new claims by UC. A second strand of financial supports are termed ‘extra-costs’ disability benefits, of which personal independence payment (PIP) is the mainstay. PIP was introduced in 2012, replacing disability living allowance (DLA).

UC/ESA and PIP each involve assessments of physical and mental functioning, which act as gateways to support; these assessments are the Work Capability Assessment (WCA) and the PIP assessment. The UK, as with other OECD countries, has implemented newly developed assessments of functioning, having previously sought to assess impairment or underlying health conditions (OECD, 2010). This shift has occurred, in part, due to a recognition that impairment is a poor proxy indicator of work capability (Bickenbach et al. 2015). Yet assessments of functioning are similarly flawed in their reliance on proxy indicators of disability, and because they involve generic conceptualisations of work, which fail to comprehend distinctive employment contexts (Bickenbach et al. 2015). A third approach to disability assessment – direct assessment of disability, or ‘real world assessments’ – aims to overcome these limitations by assessing disability or work capability as an individualised, and contextually specific, phenomenon:

“The [direct] disability approach, in its purest form, would be fully individualized and based on direct evidence… on the assumption that the true object of assessment must be the person-environment, interactive outcome rather than any intrinsic feature of the person” (Bickenbach et al. 2015: xii).

However, such real-world assessments of disability face staunch and entrenched opposition within mainstream politics, as indicated in 2011 by the then Secretary of State for Employment, Chris Grayling: ‘The one thing I am absolutely unreservedly and implacably opposed to in all of this is a real world test. Either somebody is fit for work or they are not’ (Grayling, 2011: cited in Baumberg Geiger et al. 2015: 26). Such a position is not rooted entirely in ignorance, and questions remain as to how direct assessments of disability might be operationalised. Important developments in this direction have been made (Baumberg Geiger et al. 2018), but there remains scepticism among policy makers, particularly over the paucity of evidence for the feasibility of real world assessments (Harrington, 2011: 38).

Anti-welfare critiques of benefit assessments

The WCA (2008) and PIP assessment (2012) need also to be understood as instrumental policy responses to political, economic and cultural forces, which acted to constrict the administrative category of disability both in the UK (Roulstone, 2015; Shakespeare et al. 2017) and across OECD countries (OECD, 2010). In earlier decades, during periods of national economic strength and full-employment, the contestation of disability benefits was relatively limited. However, this consensus
weakened throughout the 1990s, and the 2000s witnessed overt ministerial linking of disability benefits to inauthentic claimants and a ‘culture of dependency’ (Roulstone, 2015). Media representations of benefit claimants as ‘shirkers and scroungers’ (Garthwaite, 2011) popularised the image of counterfeit claimants within a broader political cultural-economy that saw social security systems as a prime lever of social, economic and moral deterioration (Jensen and Tyler, 2015). In closer policy terms, a primary criticism of IB (predecessor to UC/ESA) was that it did not sufficiently incentivise claimants to seek work. New Labour’s New Deal for Welfare (DWP, 2006) green paper stated this explicitly and argued that IB provided ‘perverse incentives’ that ‘trap people into a lifetime of dependency’ (DWP, 2006: 3). Extra-costs disability benefits were also maligned, and the erstwhile DLA (processor to PIP) was derided as inefficient, dysfunctional and susceptible to fraud (Drake, 2000).

A specific point of anti-welfare criticism important to our analysis concerns the role of health professionals in welfare certification. Unlike parallel administrative categories of welfare – childhood and old age – validating disability is not straightforward, and questions over the validatory role of health professionals were central to debates around IB and DLA. In relation to DLA, critics claimed that there was an over-reliance on claimant self-declaration and insufficient use of medical certification (Machin, 2017). In relation to IB, the testimonial role played by claimant’s own doctors was questioned because of their emotional and moral attachment to patients. This line of reasoning was articulated at the time by the influential think-tank The Social Market Foundation:

‘There is much anecdotal evidence of GPs feeling pressured to support their patients’ IB claims to protect good doctor-patient relations... Many GPs may also be inclined to take a wider view of their responsibilities to their patients’ welfare... They may, therefore, be well-disposed to any IB claim patients may make’ (SMF, 2005: 15).

In line with this premise, calls for reform did not question the validatory function of medicine per se, but assumed the testimonial role of claimant’s own health professionals to be flawed, their testimony based not ‘objective’ medical analysis but their duty of care to patients and the claimant’s ‘own perceptions and desires’ (Waddell and Aylward 2005:53). Subsequent UK assessment regimes would retain medical validation, but would do so in a way that ostracised personal health professionals in favour of privately outsourced assessors.

Objectivity and welfare reform

Discourses of evidence played an important role in helping to establish a political impetus and legitimising logic for reforms to disability benefits. Against the purported threats of inauthentic claimants and biased personal doctors, advocates of welfare reform promoted increasingly ‘objective’ benefit assessments (SMF, 2005, Waddell and Aylward 2005). To some, objective benefit assessments offered panacea-like redress to the ills of IB and DLA, whilst for others, the connotations of validity, reliability and fairness, meant that even the most punitive welfare reforms became palatable. This symbolic function of evidence is displayed in the Department for Work and Pensions (DWP) public consultation over the PIP assessment, which outlined the UK government’s vision for a reformed assessment regime:

“We want the new assessment to be objective and evidence-based, to ensure that support is targeted to those individuals whose health condition or impairment has the greatest impact on their day-to-day lives. A greater emphasis on objectivity and increased use of evidence will lead to more consistent outcomes and greater transparency” (DWP, 2010: 16).
Similar themes were apparent in the implementation of the WCA where objectivity, connoting efficacy and fairness, informed and legitimised reforms:

‘The end-to-end WCA process intends to evaluate objectively a person’s capability for work so that appropriate support can be provided to help them back to work’ (Harrington, 2010: 11).

‘The perception of objectivity is fundamental if the WCA is to survive in its current form’ (Litchfield, 2013: 5)

Aside from the symbolic and political function of evidence broadly conceived, the discrete principle of objectivity directly informed practical changes to the format of benefit assessments and the role of different actors within assessment regimes. As outlined above, key criticisms of IB and DLA was the centrality of claimant self-declaration and the validatory role of personal health professionals. The introduction of the WCA and PIP assessment marginalised both these knowledge claims. The PIP assessment’s predecessor (DLA assessment) involved a lengthier paper-based assessment and fewer face-to-face assessments, which afforded greater weight in the decision making process to claimant self-declaration. In the PIP assessment, claimant self-declaration was displaced by the testimonial role of commercial ‘independent’ assessors generated through face-to-face assessments. As the 2017 independent PIP review stated:

‘A key policy aim of PIP was to deliver a fairer, more transparent and more objective assessment than DLA. This would be done through a report provided by a qualified Health Professional following a face-to-face assessment with that Health Professional in most cases’ (Gray, 2017: 48).

The marginalisation of claimant testimony was also mirrored in UC/ESA through the roll-out of the WCA, as illustrated by the relative numbers of claimants undergoing face-to-face assessments. DWP figures show that in 2007/8, 39% of IB claimants were exempt from assessments (both paper and face-to-face), and of those assessed, only 53% were required to undergo face-to-face assessments. By 2010, 93% of all ESA claimants were required to attend face-to-face assessments (DWP, 2010b). This radical proliferation in the numbers of face-to-face assessments reflects a clear shift, as claimant self-declaration was marginalised in favour of the testimony of commercial ‘independent’ assessors garnered through face-to-face assessments.

Assessment reforms also addressed the purported bias of personal health professionals by affording less weight to this form of evidence. In quantitative terms, figures released by private assessment providers reveal that medical evidence is requested from claimant’s own healthcare team in only a small proportion of cases (Newton, 2018). In qualitative terms, when personal medical evidence is requested, this is done using evidence pro formas, which actively limit the scope of personal doctors to address the UC/ESA and PIP assessment criteria and focus instead on confirming diagnoses and treatment plans (Author, 2019).

Political appeals to evidence played upon populist anti-welfare tropes, and helped establish a political impetus for reforms to benefit assessments. The principle of objectivity was central in providing a legitimising logic, connoting efficacy and fairness, and promising to remedy public and political anxieties over the integrity of assessment regimes. Understanding the consequences of these reforms is aided by a consideration of what objectivity entails both philosophically and politically.
The many faces of objectivity

Superficially clear and immutable, a philosophical lens reveals the historically situated, politically contingent and ethically problematic nature of objectivity (Longino, 1990). As Daston (1992) outlines, everyday use of the term objectivity ‘is hopelessly but revealingly confused’ as it ‘refers at once to metaphysics, to methods, and to morals’ (Daston, 1992: 598). This conflation leads to a vague and ill-defined concept, which connotes a slew of values and practices, and renders objectivity with a fuzzy scientific virtue:

‘Current usage allows us to apply the word as an approximate synonym for the empirical; for the scientific, in the sense of public, empirically reliable knowledge; for impartiality- unto-self-effacement and the cold-blooded restraint of the emotions ... and for the ‘really real’, that is to say, objects in themselves independent of minds’ (Daston, 1992: 598).

Underlying each of these strands of meaning is an assumption that objective practice requires a demarcation, both rhetorically and practically, between common-sense or everyday thinking and that of scientific thought (Fine, 1998). This in turn involves the latent premise that perspectival or locally situated knowledge is untrustworthy, and that objective inquiry offers the means to abstract from individual perspective (subjective) and local conditions (relativistic) in ways that produce more trustworthy knowledge (Heldke and Kellert, 1995). As Fine (1998) argues persuasively, the pursuit of objective inquiry in this predominant mode is defined by the eschewal of the personal for the non-personal, and of bracketing-out individual perspectives in pursuit of a viewpoint of ‘no-one in particular’:

‘To do better than everyday thinking we need to be detached, impartial, disinterested, unbiased. We need to abstract from everyday concerns and disengage from common habits and private perspectives. We need to consider things from an impersonal and neutral point of view. In short, the ideal of method requires us to be no-one in particular’ (Fine, 1998: 11).

Grouping these concerns together, Fine (1998) coins the phrase ‘procedural objectivity’ in reference to the ideal of method, which regards objectivity as a function of neutrality, detachment, and disinterestedness.

It is this mode of objectivity, a procedural objectivity, which characterises both the symbolic imagining and practical realisation of ‘objective’ reforms to UK benefit assessments. Beginning with a distrust of individual perspective (the authenticity of claimants and of their personal medical professionals) and an unwillingness to accept variation according to local conditions (Grayling, cited in Baumberg Geiger et al. 2015), its response is to demand increased standardisation, greater empirical observation, and the foregrounding of purportedly independent assessors as arbiters of knowledge.

But procedural objectivity is not without limitations, and feminist and liberal epistemology draw attention to its latent consequences. Liberal critics highlight the tendency for procedural objectivity to deny alternate methods and voices, leading to depleted and less useful forms of knowledge. A liberal model of objectivity, by contrast, argues that inquiry will become more trustworthy, not less, the more open, pluralistic and democratic it becomes (Fine, 1998: 12). A similar democratising impulse is advanced within feminist epistemology, which draws attention not only to the myopic viewpoint of no-one in particular (Daston, 1992), but also the tendency for procedural objectivity to systematically oppress, exclude and symbolically disqualified alternative perspectives (Longino, 1990). As Tannoch-Bland (1998) outlines:
‘In so far as the values that have shaped the sciences pass unexamined through the scientific process to distort our understanding of nature and ourselves, objectivity is impoverished and weak’ (Tannoch-Bland, 1998: 161).

Modes of inquiry based upon the principles of disinterestedness and neutrality will, it is argued, lead necessarily to the reproduction of broader androcentric, classist, and racist social orders (Harding, 1995). Arguing instead that all knowledge emerges against a background of situated beliefs, a feminist reading rejects the possibility of aperspectival knowledge altogether, and focuses instead on the ways that power operates to promote or deny different knowledge claims.

As outlined above, political appeals to evidence and the contestation of knowledge-making processes – how disability may be known and by whom – were central to the symbolic imagining and practical realisation of disability welfare reforms. The aim of this paper is to examine the consequences of reforms made to UK disability benefits assessments in the name of objectivity, both for disabled people accessing benefits, and also in terms of the trustworthiness of assessments. In discussion, we consider assessment reforms and the lived experience of claimants against the above discussion of objectivity, and imagine alternative principles more likely to lead to trustworthy assessments.

**Study design and research methods**

Given the aim of this study, a qualitative in-depth interview design was adopted. In total 50 UK disability benefit claimants took part in in-depth interviews, which focused on recent (3 years) experience of UC/ESA and PIP. Participants were sampled purposively, based on their having accessed UC/ESA and PIP. Interviews were conducted as part of a study funded by the Disability Benefits Consortium, which explored the impact of UK welfare reform on the lives of disabled people. The host institution’s Faculty of Medicine and Health Sciences research ethics committee provided ethical approval for the study (8th March 2018).

Study participants aged between 21 and 65 years (average age of 45) and included 25 men and 25 women. The sample included six British Asian participants, one white non-British participant, one mixed race participant, and 42 White British participants. The sample was diverse in terms of the impairment type, and included people with physical impairment and mental ill-health, sensory impairment and learning disability. Participants were asked to define their impairment, and each quotation presented in the findings section is accompanied by a description in these terms.

[Table 1 here.]

A mixture of face-to-face and telephone interviews were conducted, and whilst both type of interview generated distinct data, subsequent analysis highlighted common themes across each. A topic guide co-produced with disabled people’s organisations guided interviews and included questions about participant’s personal and financial circumstances and their experience of accessing benefits. Each member of the research team conducted interviews, which were audio-recorded and transcribed verbatim. Data storage, administration, and analysis were conducted using QSR Nvivo 11.

Thematic Analysis (Braun and Clarke, 2006) provided the framework for analysis. Analysis involved initial coding of interview transcripts, which was data driven rather than being led by pre-existing theory. Once the entire data set was coded, the research team searched for themes within and between codes. This process resulted in a thematic analytic framework, which received continual critical review within the research team.
Findings

Data reveal an impersonal and inhumane assessment processes, which threatens the wellbeing and selfhood of claimants. For many, increasingly detached and disinterested assessments failed to adequately comprehend disability. Finally, data show that the pursuit of procedural objectivity has created systems that permit inequity to flourish, in which claimants with fewer personal, social and economic resources are least likely to succeed.

Claim forms: standardised efficiency over health and selfhood

Claimants applying for UC/ESA or PIP must first complete claim forms, which generate standardised accounts of functional impairment, and determine how claims proceed. Nearly all informants in this study spoke about this process being onerous and inhumane, and for some, it was a deeply damaging experience. Cath, for example, a 62-year-old woman with visual impairment said ‘filling the form in threw me into a depression’; she explained that completing the PIP form forced her confront her loss of functioning and to re-evaluate her sense of self:

“You have to enumerate all the things that you have difficulty with. There were some things on the form that I thought, “no, that’s not me”... but when I thought about it, it was correct... So you become acutely aware of everything that you have difficulty with, and that made me depressed” (Cath, 62-year-old woman, visual impairment).

Far from being a simple administrative task, completing UC/ESA and PIP claim forms may be a deeply moral endeavour, which stigmatises claimants and fundamentally threatens their preferred visions of selfhood. Moreover, the need to complete claim forms comes, necessarily, at a time when claimants face acute physical, mental and financial crises. In this context, impersonal standardised data capturing tools, completed remotely and without support, represent the prioritisation of bureaucracy over health and wellbeing. The consequences of this were revealed in stark terms by Sarah, a 45-year-old woman with dystonia, anxiety and depression. Sarah had only recently encountered the benefits system for the first time and spoke proudly of her work ethic: ‘I want to get back to working, I like to work... I am a worker’. Claiming benefits was deeply troubling for Sarah as it undermined the moral basis of her sense of self and identity: ‘I don’t want to go down the road of “oh I am disabled and I’m claiming benefits”. As she spoke about completing the ESA claim form, Sarah revealed a process that had left her feeling stigmatised, racked with guilt, and labelled as counterfeit:

‘They all said ‘represent yourself with the DWP as if you are having your worst day’. [sighs.] It’s something I really struggle with, thinking about how to present myself. To jump through their hoops, when everyone I know thinks I am entitled to that money but there is something in me that feels guilty about being in this situation, I feel embarrassed about it. I am having difficulties, but I am very angry at a system... There is a constant struggle in my mind and it takes a lot of thought. It is very stressful. I am legitimately struggling in lots of ways, and yet their way of checking you out is bizarre’ (Sarah, a 45-year-old woman with dystonia, anxiety and depression).

Evidencing eligibility in this format was in and of itself distressing, but was not the end of the process; the face-to-face assessments that typically followed compounded this stress. It is to an exploration of this stage of assessments that we now turn.

Face-to-face assessments and the human cost of disinterestedness
Reforms to benefits assessments have witnessed the marginalisation of claimant self-declaration in favour of face-to-face assessments conducted by commercial providers. The purported value of face-to-face assessments is that they deliver increasingly valid and reliable assessments by virtue of their independence and standardisation (Gray, 2017). However, for many informants in this study, the consequence of these increasingly disinterested processes were impersonal and emotionally damaging assessments. A clear example was given by Eva, a 56-year-old woman with osteoarthritis. Like many participants, Eva expressed desperation and shame at the prospect of seeking benefits, saying: ‘nobody wants to be in this position... to come to this, I don’t want to be like this’. Eva described her PIP assessment as ‘horrendous’ and singled out the assessor’s officious manner:

“There’s a lack of empathy, that person really isn’t interested and doesn’t even try to pretend to look interested. You talk about something that’s very painful or difficult, and there’s no reaction... nothing. It’s just bashing away on the keyboard... these people are health professionals – nurses or physiotherapists – you’d tend to think they are more empathetic” (Eva, a 56-year-old woman, osteoarthritis).

Hashim, a 32-year-old man with mental ill-health, recalled similar experiences of the ESA face-to-face assessment. Applying for ESA was Hashim’s first encounter with the benefits system following a recent episode of psychosis; he recalled his shock at the conduct of his face-to-face assessment, and in particular, the prosecutorial role assumed by the assessor:

“I felt surprised by it... I’ve never been to the police station for an interview, but it felt like I was at the police station and they were questioning what I was saying. They were taking copious amounts of notes. They didn’t believe me or understand my situation”.

A further fundamental concern for many informants was that face-to-face assessments did not provide realistic insight into their functional capability. This was especially the case for participants with mental health problems, fluctuating conditions, hidden impairments, or illness that remain scientifically misunderstood (such as ME). For these participants, face-to-face assessments were a blunt, even discriminatory tool, which generated a misleading picture of functioning. Maggie, a 62-year-old woman with Parkinson’s disease, spoke of her recent transfer from DLA to PIP; Maggie stated clearly that her face-to-face assessor had mistaken her fluctuating symptoms as inconsistent with the account she had given in her initial claim form:

“She seems to say that my comments on the day were inconsistent with what I’d written... but as I pointed out to her, Parkinson’s is a very inconsistent condition. She should have known that. No two days are the same”.

In another example, Tim, a 52-year-old man with mental ill-health and narcolepsy recounted his WCA assessment and suggested that his assessor had mistaken his scrupulously neat appearance as an indication of high mental functioning:

“I wouldn’t go out the house unkempt or unshaven, with dirty clothes or anything like that. I just wouldn’t do it. And perhaps that’s one of the pointers to depression, that people would neglect their appearance, but this was important to me. The fact that I was smart and I was articulate and answered the questions in-depth... actually counted against me when it came to his report, but that was just on the day”.

The example given by Ellie, a 55-year-old woman with ME, captured the problematic nature of face-to-face assessments for both scientifically unexplained conditions and hidden impairments. Ellie
expressed a preference for paper-based assessments, and reasoned that the hidden nature of her illness put her at a disadvantage in face-to-face assessments:

“I think for some people with different disabilities it’s a lot easier to show; I have nothing… (visible) When you’ve got a major physical disability, or if you’ve had a head injury or something like that, you cannot function. With some of these illnesses, there’s nothing to show for it”.

**Personalised medical evidence marginalised**

As with claimant self-declaration, the testimony of personal health professionals have also been marginalised, driven by the supposed propensity of claimant’s own health professionals to provide unduly supportive statements (SMF, 2005; Waddell and Aylward 2005). This marginalisation was apparent in the accounts of many participants, and held clear implications for the trustworthiness of some assessments outcomes. Lisa, a 48-year-old woman, reflected on the difference between the PIP assessment and the erstwhile DLA. With a history of accessing both benefits, Lisa explained that her recent PIP assessment relied more upon the judgement of the commercial assessor, and did not adequately incorporate the testimony of her own medical team:

‘I don’t believe that they [commercial assessors] read everything and I don’t believe that they believe anything you say, or anything that your medical specialists say. For me, that is the big difference now… that you’re always believed to be a fake. I think at that point [DLA] you could send a specialist letter in with your full diagnosis, with a list of your meds and a full explanation of how it affects you. Now I feel that even though I’ve been very thorough with the evidence, it is actually a waste of time… The decision makers (DWP) rely on the assessor, but it is completely skewed against you and real evidence’ (Lisa, a 48-year-old woman, chronic migraine, fibromyalgia, anxiety and depression).

Lisa’s reference to personal medical testimony as ‘real evidence’ implies a correspondingly artificial quality to the observations made by commercial assessors, rooted in their detached unfamiliarity with her unique physiological, psychological and social circumstances. For Lisa, relying on this latter form of evidence, and denying the testimony of her own medical team, leads to a partial understanding of her functional capability.

Similar concerns were also expressed by Irene, a 32-year-old woman with ME. Following a 2016 PIP assessment, Irene was awarded enhanced rates of mobility and daily living – a level of award she felt fairly reflected her needs. However, her latest PIP review, in 2019, resulted in Irene losing the mobility component entirely. Irene was clear that this decision to had not taken into account the detailed medical evidence provided by her GP and hospital consultant: ‘they seem not to take into consideration the medical evidence I sent in, they seemed to just say what the ATOS report said and that’s what they went by’. Irene explained that neglecting this information, and relying on the judgement of a commercial assessor, resulted in a decision that fundamentally misunderstood her level of functioning:

‘That ATOS assessor, although they are a healthcare professional, they don’t know me as well as my occupational therapist, who I’ve been working with since 2015. It seemed strange to me that they would put more of the weight of evidence on the ATOS report [commercial assessor]. I understand it’s there to provide evidence, but when the report contains an account that isn’t correct – the only way to challenge that was with evidence from medical professionals who know you and your condition. I’m under the care of a specialist clinic, I’d
provided a letter from them, but that wasn’t given equal weight’ (Irene, a 32-year-old woman with ME.)

**Procedural objectivity: barrier to trustworthy assessments and a lever of inequality**

Reforms to disability benefit assessments have seen claimant self-declaration and personalised medical evidence marginalised in favour of commercial face-to-face assessments. These reforms seek to obtain objectivity in a procedural sense, and in pursuing an ideal of method, aim to ensure assessments that are free from bias and the idiosyncrasies of local context (Fine, 1998). However, data in this study indicate that far from making the product of assessments more trustworthy, these reforms have created systems that permit inequity to flourish. As the following excerpts show, access to personal, social and economic resources make compiling an effective case more likely. For people lacking in these forms of capital, a double disadvantage is delivered by a system that denies support, and marginalises self-declaration and personalised medical evidence in pursuit of procedural objectivity.

John, a 43-year-old man with depression, was typical of many participants in that he found assessment processes onerous and disempowering – ‘It’s so time consuming, it’s playing with my life’. John also epitomised a sub-group of participants for whom the assessment process was impenetrably complex, and for whom the lack of available support and advocacy was striking: ‘no one has ever taken the time to tell me how it all works’. John’s PIP assessment resulted in an enhanced rate for daily living support, but his recent UC application was rejected entirely. John attributed this decision, in large part, to the fact that he did not understand the system well enough to compile an effective case for support. When asked whether completing forms and written communication were a strength, John replied ‘not really’, adding;

‘*Filling in those forms, it’s very political really, for them to get the answers that they want from you. It’s quite bizarre how you have to put things. Sometimes I read things that I want to read or see things that I want to see, so I miss what they’re asking me. I think the questions in some ways are like trick questions and they’re trying to trick you into giving different answers*’ (John, a 43-year-old man with depression.)

This was by no means an isolated example and many other participants appeared ill-equipped to navigate the system successfully. Hashim, a 32-year-old man, lost his job following a recent mental health crisis and revealed a system totally lacking in advocacy and support. Following his UC application, Hashim was required to engage in work readiness activities or face sanctions. Reflecting on this decision, Hashim suggested that his lack of knowledge meant he could not effectively present his case for support:

‘*I just filled in all the boxes, but I was then told it depends on what you write and how you write it, and that’s what I realised... that would actually determine how much I got, so if you put in certain key words, then that would reflect on you getting certain types of support and I didn’t do that at all*’.

For other participants, the support of family members or other disabled people well-versed in the benefits system were key to successful claims. William, a 27-year-old man with cystic fibrosis and osteoporosis, spoke of his experience claiming PIP. William’s initial claim was rejected entirely – a decision he appealed with the support of his family. After a long and complex tribunal process, William was ultimately awarded enhanced mobility and standard daily living rates of support. As he spoke about the assessment process, it became clear that William’s success was due, in large part, to the administrative and emotional support given by his mother:
'My mum filled out the forms for me... we sort of do it together, but to be honest mum did do quite a lot of the paperwork ... I've got to be honest, it's not my forte. My mum handles my benefits and paperwork because I wouldn't have the confidence to do it myself ... my confidence isn't 100% with that sort of thing... trying to keep on top of my health as well would have been very difficult. I could have put more strain on my health'.

Economic resources were central to the success of other participants. Alison, a 47-year-old woman with functional movement disorder, said that successful benefit claims required sophisticated knowledge of assessment criteria and legislation, and that despite having a doctorate, she felt unable to navigate the process without privately funded advocacy (FightBack4Justice):

'I no longer trusted myself to fill in forms, because I don’t know the latest legal ruling, I don’t know the latest case law and I felt that you actually need that level of knowledge to fill this form in now. I refused to fill it in, and I paid the FightBack4Justice [sic] to do it'.

Alison’s PIP assessment saw her awarded enhanced rates of support for both mobility and daily living components. This success, Alison explained, was due to her ability to fund advocacy and supporting evidence; she paid for multiple Data Protection Act (DPA) requests, meaning she secured her medical records and documentary evidence of her care and occupational adaptions: ‘that was useful because I got a bit back from the OTs and the wheelchair services... Well, it’s essential basically’. Alison was clear that this evidence came at a cost, both in terms of her time, but also financially:

“That’s a tenner every time you send something out. So I spent £30 just on DPA requests from the relevant people. If I’d had multiple consultants and everything, that would have been more. So it was the GP, the OT and the wheelchair services was what I got DPAs on”.

Access to private healthcare professionals was another lever of success as it meant participants were able to source more effective supporting evidence. For medical evidence to be effective, it must not only confirm diagnoses and medications, but needs also to address the functional impact of illness and impairment. Many participants questioned the value of evidence sourced from NHS health professionals on the basis that it did not address these criteria, whereas informants with private healthcare were able to acquire evidence tailored to these specific requirements. Rachel, a 65-year-old woman, explained the significance of this testimony:

‘My private psychiatrist just wrote whatever without any charge and was very helpful... he did talk about the prognosis and long-term and that it would affect me and my ability to maintain a purposeful employment long-term. He was quite good at that, my GP less so. But she did write me a letter of support confirming my diagnosis. And I also had my letter from my consultant because I went private... my husband had BUPA’ (Rachel, a 65-year-old woman with ankylosing spondylitis, osteoarthritis, diverticular disease and cervical dystonia.)

Social position, or class, was another factor enabling some to make successful claims. Paul, a 52-year-old man with cerebral palsy, spoke in detail about the process of attaining supporting evidence from his NHS doctor. In doing so, Paul suggested that his social position meant he could negotiate more effective evidence:

“I drafted guidance notes for each healthcare professional. And as you can tell, I’m a white, middle-class, articulate, educated person so one of the things that I do is create relationships with the healthcare professionals who are in my life to get them to do what I want them to
do, whether that’s writing letters, or prescribing me certain treatments or referring me to certain people and so on.. It was crucial”.

Discussion

In the decade preceding the WCA and PIP assessment, political and cultural forces acted to constrict the administrative category of disability (Stone, 1984). Anti-welfare narratives depicted erstwhile assessment regimes as overly-permissive and fundamentally unfair (Drake, 2000; DWP, 2006); benefit claimants were maligned as inauthentic (Garthwaite, 2011); and personal health professionals were labelled as biased validators of welfare (SMF, 2005). Against these purported threats, advocates of welfare reform made populist appeals to evidence and called for increasingly objective assessments of functioning (SMF, 2005, Waddell and Aylward 2005). Under the banner of objectivity, new assessment regimes fundamentally altered the way disability is assessed and evidenced. Claimant self-declaration and personal medical evidence were both marginalised in favour of increasingly standardised claim processes, the cornerstone of which continue to be face-to-face assessments conducted by commercial assessors.

This paper has set out that these reforms were informed by a mode of objectivity that idealises method; a procedural objectivity, which regards objectivity to be a function of methodological neutrality and disinterestedness (Fine, 1998). The immediate consequences of these reforms are visible in the experience of claimants completing initial claim forms. This epistemological practice has ontological consequences, and many participants reported deeply damaging experiences, during which their preferred visions of selfhood were denied by a system that demands claimants directly confront their loss of functioning. The requirement to complete these forms typically comes at a time when claimants face acute physical, psychological and financial crises; for some, this inhumane process led to added mental health crises.

Promising greater independence, face-to-face assessments proliferated under reformed assessment regimes (DWP, 2010b). But many participants in this study reported that commercial assessors lacked empathy, and some perceived face-to-face assessments to be hostile. Face-to-face assessments offer only a brief and partial snapshot into claimant’s lives, and participants expressed concerns that they gave an unrealistic impression of functioning. This was especially prominent among participants with mental health problems, fluctuating conditions, hidden impairments, or illnesses that remain scientifically misunderstood (such as ME). For these participants, face-to-face assessments are a blunt, even discriminatory tool.

The marginalisation of personal medical evidence was justified by the supposed propensity of claimant’s own health professionals to provide unduly supportive statements (SMF, 2005, Waddell and Aylward 2005). However, members of claimant’s own healthcare team are often the people most qualified to understand the complex interaction between an individual’s physiological, psychological and social circumstances. Participants in this study routinely reported that personal medical evidence was given insufficient weight in the decision making process, and for some, this appears to have resulted in highly dubious outcomes.

Perhaps the most striking consequence of reforms, however, are those relating to social reproduction. Far from making the outcomes of assessments fairer, reforms have created systems that permit inequity to flourish. Interviews revealed an increasingly detached and impersonal assessment process, set against a broader welfare landscape in which advocacy and support have been retrenched. In this context, attaining a valid and reliable assessment was, for many participants, contingent upon personal, social and economic resources. For disabled claimants
lacking in these forms of capital, a double disadvantage is delivered by a system that denies advocacy, and distrusts claimant self-declaration and the testimony of claimant’s own health professionals.

These findings echo previous studies into the lived experience of claiming disability benefits, which highlight the stigmatising and alienating features of social security systems, as well as the onerous and injurious consequences for claimants navigating these systems (De Wolfe, 2012; Holler, 2020; Wright, Fletcher and Stewart, 2020). To this literature this paper adds the explicit linking of these outcomes to, in part, a tacit epistemological standpoint – that of procedural objectivity – and a broader critique of political appeals to evidence in service of retrenchment-oriented welfare reforms.

At the heart of debates around welfare are questions of trust; trust in the genuineness of claimants, trust in the legitimacy of medical testimony, and trust in processes of assessment itself. Anti-welfare critiques play to these concerns and gain traction when the authenticity of claimants appears questionable, where the motivation of personal medical professionals is doubted, and when assessment regimes appear overly permissive. The questionable veracity of these concerns notwithstanding, each exerts a powerful emotional hold over public opinion and shapes attitudes towards disability benefits (Baumberg Geiger et al. 2018). Political appeals to evidence speak directly to these anxieties, and procedural objectivity offers appealing, if ultimately specious, remedies. Despite connotations of fairness, procedural objectivity is not a politically neutral epistemological position. This ideal of method implicitly accepts privilege and disadvantage, and benefit assessment regimes informed by this logic will necessarily advance existing social, economic, and health inequalities. Liberal and feminist critiques of procedural objectivity predict that pursuing an ideal of method will result necessarily in impoverished modes of knowledge and the reproduction of existing social orders (Daston, 1992; Fine, 1998). These critiques anticipate our findings that extant assessment regimes do not adequately conceive of disability, and act as a lever of existing inequality.

How then might more trustworthy outcomes be realised? Practical features of the WCA and PIP assessment need reform, and direct disability (or real world) assessments must be championed. If the true object of disability benefit assessments are disability understood as the interaction between impairment and environment, then assessment regimes cannot continue to treat disability as an intrinsic feature of the individual (Bickenbach et al. 2015). Direct disability assessments aim to assess disability as an individual-environment interaction; to overcome the reticence of policy makers to such assessments, their nascent evidence base must be prioritised and developed (Baumberg Geiger et al., 2018).

Of equal importance to practical reforms are questions of values: assessment reforms have been driven by an ideal of method, when it is the product of inquiry that matters most. For welfare to reach those in need, procedural objectivity must be tempered by the corresponding value of objectivity as product, understood as the prioritisation of trustworthiness in outcomes over methods. This shift, informed by pragmatism, rejects the ideal of method in favour of the view that the trustworthiness of outcomes is paramount – the proper sort of inquiry is that which gets things right (Fine, 1998). As a guiding principle, objectivity as product rejects the procedural distinction between objectivity on the one hand, and subjectivism and relativism on the other (Fine, 1998; Harding, 1995). Instead, it proceeds from a liberal belief that knowledge becomes richer and more robust when alternate voices are heard. To this end, benefits assessments will be strengthened by trusting, valuing, and meaningfully reincorporating the voice of claimants and the testimony of personal health professionals. This is not to say that assessments ought to be decided solely on the
basis of these knowledge claims, but in assuming both to be inauthentic, current assessment regimes deny both their rightful place in the decision making process.

Objectivity as product also entails the feminist demand that inquiry acts directly to overcome structures of oppression and symbolic disqualification. Rather than asking how processes of inquiry may be made more impartial and less personal, objectivity as product demands that observers become increasingly responsible, both to the product of inquiry, but also to the subjects therein (Heldke and Kellert, 1995). Procedural objectivity seeks to bracket out extraneous factors, prioritise internal validity, and so limit the role of individual perspectives or local conditions. But as this paper has shown, this approach simply denies advocacy and support to those most in need, and means successful claims are often contingent upon access to personal, social and economic resources. A trustworthy assessment process must ensure that all claimants have access to the support needed to make effective benefit applications, regardless of personal resources. Only when this is realised may claims be assessed in the knowledge that the influence of private resources are tempered by public support. At its core, this is a call for more democratic assessment processes, which not only accommodate alternative voices, but also seek to disrupt exclusory social order, overcome disabling barriers, and promote inclusive modes of knowledge. Returning to the question of values, a democratic reappraisal of objectivity represents the foregrounding of its ontological and moral dimensions (Daston, 1992), and promises outcomes that are more trustworthy by virtue of their being more just.
References


