



ARTICLE

Why is Lived Experience Absent from Social Security Policymaking?

Ewen Speed^{1*}  and Aaron Reeves² 

¹Professor of Medical Sociology, School of Health and Social Care, University of Essex, CO4 3SQ, UK and

²Professor of Evidence-Based Social Intervention and Policy Evaluation, Department of Social Policy and Intervention, University of Oxford, OX1 2ER, UK

*Corresponding author, email: esspeed@essex.ac.uk

(Received 7 April 2022; revised 21 November 2022; accepted 18 December 2022; first published online 20 February 2023)

Abstract

Processes of public engagement in decision-making and research are increasingly discussed as ways of addressing democratic deficits in high-income countries. In this paper, we explore why these processes of engagement and involvement in the UK have been less successfully incorporated into social security policymaking aimed at the out-of-work by drawing a comparison with health policy, a sphere in which these processes have now become orthodox (albeit imperfect). There is, for example, no formal or institutionalised imperative to involve people with lived experience of out-of-work social security benefits in processes of policy development. Government departments might focus group new policies with members of the public or hold periodic discussions with beneficiaries but in recent years there have been a number of major reforms to out-of-work social security which have been developed almost entirely without involving those affected. This would have been unacceptable in the health policy arena. We argue that this difference is rooted in structural differences in how the field of power for this form of social policy is organised, in the different social imaginaries which construct patients and out-of-work beneficiaries, and in the limited scope for solidarity and collective action around resisting the stigmatisation of out-of-work beneficiaries.

Keywords: democratic deficit; stigma; collective action; participation; social security

Introduction

The decision-making processes involved in creating social policies targeting those who are out-of-work have been marked by a democratic deficit in which the people most keenly affected by those decisions – that is, beneficiaries themselves – are persistently excluded from designing those policies. The importance of lived experience¹ is, of course, not entirely ignored by governments but there are, certainly in the UK, very few formal mechanisms through which out-of-work social security recipients can be involved in the design of these largely flat-rate and means-tested

© The Author(s), 2023. Published by Cambridge University Press. This is an Open Access article, distributed under the terms of the Creative Commons Attribution licence (<http://creativecommons.org/licenses/by/4.0/>), which permits unrestricted re-use, distribution, and reproduction in any medium, provided the original work is properly cited.

forms of social security policy; and where these mechanisms do exist, the statutory duty to respond to those voices is often weak.

This lack of participation in policymaking aimed at means-tested benefits for the out-of-work has not gone unacknowledged or unchallenged. Academics (Beresford and Croft, 2016; Mcintosh and Wright, 2019), charities (ATD 4th World), and think tanks (Joseph Rowntree Foundation) have all addressed this democratic deficit in this area of social security policy by both making the case for participation and proposing formal governance mechanisms that would incorporate these voices into decision-making processes. There have also been successive and recent efforts to create participatory approaches to evidence gathering, such as the Poverty and Truth Commissions – however, these efforts are typically local, rarely institutionalised, and very often precarious.

Rather than make the case for participation or examine how such participation might work in practice, we explore why certain forms of participation within policymaking remain uncommon in this domain of social security policymaking, and ask what this might tell us about participation more generally in the policy context. This means we are not primarily concerned with whether participation, particularly participation by experts with lived experience, delivers social goods (such as improved service delivery or value for money), especially because such benefits are hard to identify and replicate (Madden and Speed, 2017). Instead, drawing on Dean's (2017) work, we are interested in why participation in social security policymaking has continued to be governed by the logic on 'arbitration and oversight' rather than the logic of 'knowledge transfer' (or even 'collective decision-making') more evident in the health setting. This allows us to see how certain ideological or political motivations might be covered over by appeals to participative legitimacy (Dean, 2017).

In this light, the absence of lived experience in social security policy is especially striking given how dominant issues of 'voice' and 'choice' have been in other policy areas (Speed et al., 2020) – for example, British health policy over the last thirty years. In the health field, it would be unacceptable to pursue policy changes (O'Shea et al., 2017), conduct evaluations (Russell et al., 2020), or even organise provision without some involvement of patients (Boote et al., 2015). However, this is not to say that health policymaking does not have a democratic deficit – there are important and well-documented problems with the processes of involvement used in health policy (Madden and Speed, 2017). Instead, our claim is that, despite relative similarity in terms of purportedly caring for the end user through effective policy provision, health has far more readily incorporated lived experiences into its decision-making processes than social security.

This is the basic puzzle motivating this paper: why is it the case that service users are often involved in health policy/delivery but not in social security policy/delivery, which is ostensibly an allied area of state provision? This becomes particularly salient when we consider the current UK social security policy context, marked by a sustained period of reform intended to further develop activation models of welfare provision. One notable example of this shift includes the creation of the Work-Related Activity Group (WRAG). Those assigned to the WRAG were often disabled people who were re-assessed as being 'fit for work' and who were then expected to actively participate in a range of 'back to work' activities. Such reforms are precisely the situation where involvement of people with lived experience would

be pertinent and useful. Moreover, this activation model of social security is where the fault lines between participation in health policy and social security policy are most visible, where disabled people simultaneously experience choice and voice in a health sphere and compulsion and silence in a social security sphere (Mehta et al., 2021).

Our argument is that the minimal contribution lived experience makes to social security policy can be best explained if we consider the structural positions of the different service users (who somewhat obliquely can actually be the same people at the same time). That is to say, much of the reason for this difference between health policy, and social security policy is a fundamentally different conception of who the end users are and the ‘capital’ these actors are afforded in their respective fields of action (Bourdieu, 1979). We argue that these differences make it more difficult (albeit not impossible) for out-of-work beneficiaries of means-tested social security to hold government to account in the same way that health care service users might, because the identity of an out-of-work beneficiary is much more stigmatised in comparison to the health care service user. The subject position (Fahy and Smith, 1999) of out-of-work beneficiaries of means-tested social security means that the only thing they are expected or able to hold to account are themselves. This raises significant questions about how social security policy and practice are constructed such that the sole provider of social security is largely unaccountable (other than at the ballot box).

In this regard, we develop three broad claims. First, the absence of lived experience is partially explained by a lack of effective accountability mechanisms countervailing the state’s influence on social security policy (Light, 2010). Second, the social imaginary which constructs patients and out-of-work beneficiaries of means-tested social security is fundamentally different, and competing narratives regarding these beneficiaries are promoted by organizations that are structurally weak with respect to government (Somers and Block, 2005). Third, there are a number of difficulties with positively identifying with the label ‘out-of-work beneficiary’ (such as the transitory nature of this support) that undermines the scope for solidarity and collective action around reclaiming and resisting the social imaginaries which stigmatise out-of-work beneficiaries (Tyler, 2020). However, before tackling these issues directly, we situate these questions in the context of our theoretical framework.

Logics of equivalence and difference within fields

Our argument draws on two theoretical traditions to examine how it has been possible to disavow participatory and democratic approaches to social security policymaking. We conceptualise the health and social security policymaking spaces as fields in which different actors (service users, the state, and others) are located in particular positions in relation to each other (Krause, 2017; Martin, 2003). These relational positions within the field matter because they come with certain resources (or ‘capitals’) which can be deployed for strategic action (Bourdieu, 1979; Fligstein and McAdam, 2011). Moreover, the forms of strategic action these capitals enable are still deployed by actors within these fields according to some logic (Martin, 2003). In this sense, then, fields vary both in the structural positions

that can be occupied within them, the relations between those positions, and the logic which governs claims-making processes (Krause, 2017).

Comparing these policymaking spaces as fields is useful because these spaces share two similarities. The first concerns the set of actors that are put in relation with each other (Krause, 2017). For example, both the social security and health policymaking fields are spaces of mixed welfare provision in which the state is intimately involved in both financing and providing services and in which citizens, as service users, are the end users. The second similarity is rooted in the fact that the specific actors occupying these positions are often the same in both fields. The health service users in the health field may also simultaneously be social security claimants (service users) in the social security field.

Fields operate according to some logic and to elucidate how the logic of these two policymaking fields varies (Phelan, 2011) we draw on the work of Laclau (1996), and Glynos and Howarth (2007). These theorists pay particular attention to processes of equivalence and difference within logics of practice, which are here regarded as the underpinning grammars which are used to articulate political practices within a policy field. By focussing on the logics of a field, the analyst, through consideration of the performative practice of policymaking, can trace and elaborate the rules that underpin those practices. These logics are not fixed. They can vary from field to field in part because institutional configurations influence how these practices and logics operate (Glynos and Howarth, 2007). Moreover, although other articulations are always possible, the dominant regime tends to enjoy a hegemonic position whereby it is able to mitigate and undermine any counter logics. As a result, we argue that the forms of capital available to different actors within these policymaking fields are organised according to distinct processes of equivalence and difference, and that these processes alter the social rationalities that characterises social security and health more broadly. In other words, these political logics of equivalence and difference organise the relations between actors in the field because they bestow forms of relational power in the policymaking process.

To unpack this a bit more, a logic of difference is concerned with practices which seek to maintain existing structures (Glynos and Howarth, 2007) by actively breaking down any equivalences that people might make in opposition to the status quo. It is predicated on accentuating differences between potential allies such that they are unable to effectively oppose a dominating other. In this context, social demands and identities are managed in 'ways that do not disturb or modify a dominant practice or regime in a fundamental way' (Howarth, 2010 p. 321). This is accomplished through accentuating the differences between groups in order to prevent the articulation of a generalised demand based in their common experience of material disadvantage. This is accomplished through implementation of policies which can be seen to address 'some (or all) of the concerns expressed by various groups or subjects, thereby preventing the linking together of demands' (ibid, p. 321). Not all groups' demands are met – rather, through the logic of difference, policy practices effectively operate on a principle of 'divide and conquer' whereby the dominant regime seeks to separate the population into particular communities or groups. The logic is predicated upon and operates through the identification of difference between groups. Policy then operates on a logic of promising to meet the needs of some of those groups – i.e. welfare nativism splits populations into those 'entitled' to

welfare and those not. The subsequent operation of these different groups then prevents the articulation of demands and identities into a generalised challenge (perhaps mobilised around social class) to the dominant regime (Glynos and Howarth, 2007). Instead, a series of minority groups, (for example, identified through their race/ethnicity) are further marginalised and excluded.

However, a logic of difference is not enough, on its own, to maintain dominance within any particular field. The perpetuation of perceived differences between groups could be undermined – for example, through participative, democratic processes initiated at community level. As such, there is also a need for some unifying logic which might operate across specific groups. It is in this context that the logic of equivalence comes into play. The equivalence, as De Cleen, Glynos and Mondon (2018) outline, is not necessarily that particular groups are seen to (positively) have the same interests in common (i.e. have equivalence). Rather, the logic of their unity is divisive rather than solidaristic, in effect they are united against a common enemy. In the context of welfare provision in the UK, we can clearly see this logic of equivalence at work in George Osborne’s speech at the Conservative Party conference. ‘Where is the fairness’ he asked ‘for the shift-worker, leaving home in the dark hours of the early morning, who looks up at the closed blinds of their next door neighbour sleeping off a life on benefits’ (Patrick and Reeves, 2020)? Osborne is deploying a logic of equivalence when he notes that the Conservative Party ‘speak for all those who want to work hard and get on’ and who are frustrated by those who do not. In this example, logics of difference function to identify a series of groups as undeserving of welfare support, and then a logic of equivalence seeks to unify all those not in those groups (the hard-working shift-workers) against those undeserving others, such that ‘strivers’ are pitted against ‘skivers’. Similarly we see a logic of equivalence played out within those on social security benefits, who tend to employ a kind of ‘defensive form of citizenship engagement and claim making’ when they draw distinctions between their own entitlement in contrast to others who are deemed less deserving (Patrick, 2017). These are both current examples of the logics of difference and equivalence at play, operating in the interests of the dominant regime.

This characterisation stands in stark contrast to dominant logics of difference and equivalence we see among health service users. NHS nativism has, no doubt, informed policymaking in recent years, but the logics of equivalence appear to be quite different in the context of the health service. Here, the underserving recipient is far less easily situated as an ‘equivalent other’ that frustrates or endangers the service. In fact, efforts to deploy the same kind of ‘deservingness’ rhetoric in a health context have been treated disparagingly (e.g. Jeremy Hunt’s suggestion that pharmaceutical packaging be marked by ‘funded by the UK taxpayer’) and have failed to gain any policy ‘grip’. There is a clear line of difference between these two fields, despite the fact that the self-same citizens may simultaneously be health service users and out-of-work beneficiaries of means-tested social security. The closest similarity in health context might be talk of ‘bed-blockers’ (Moreau and Rudge, 2019) but this has nowhere near the same grip on the public imaginary that the strivers/skivers trope has. To address this apparent contradiction, we return to how these logics of difference and equivalence are underpinned by the structural position of service users and how these logics undermine the case for more democratic policymaking in the social security space.

Structural position of service users and the absence of countervailing powers

As we have already argued, out-of-work beneficiaries of means-tested social security are located in a very different structural position in the field of power than health service users. The field of power describes the positions of different actors within the space of social relations (Krause, 2017), and these fields reflect (in slightly different ways) broader trends. For example, we know that the specific actors are similar in both fields but the capitals afforded to these actors are quite different. Both fields are spaces of mixed welfare provision, but, despite this general similarity, the resources available for strategic action (capitals) to these same individuals are radically different in these fields. In our view, this is because these fields are rooted in divergent logics of difference and equivalence as described above. The logics of these spaces determine both who has power within a field but also who is able to form alliances with whom. In other words, logics of difference make some alliances harder to form (such is the extent of this stigma that, if people are simultaneously a patient and an out of work beneficiaries of means-tested social security, they are far more likely to identify as a patient). Likewise, logics of equivalence make them unintelligible (patients unite against malingerers, for fear they might be so labelled, just as strivers rail against skivers).

Our primary claim is that the field of power for social security policymaking is so dominated by the state that social security beneficiaries have fewer opportunities to forge power blocs which can extract claims from the state. This is because the state is principally responsible for creating the practices that structure social security systems and has successfully managed to avoid the identification of any democratic deficit in the social security policy field – this marks the articulation of a very effective logic of equivalence unified against out of work beneficiaries of means-tested social security characterised as skivers. Health services users, by contrast, have more opportunities to form power blocs because of two key differences in the structure of the health policy field. The first is the presence of professionals (with a recognised form of accreditation and expertise) who might hold government to account (and create opportunity to counter the logic of equivalence which vilifies the profession – see Speed and Gabe, 2019); and the second is the relation between service users and market actors (which creates opportunity to counter the logic of difference across different groups within the field).

First, while both fields are organised by the struggles over resources among four key actors – the state, professionals, market actors, and service users – the relative power of these actors is very different in the health field compared to the social security field. The state and medical professionals are dominant within the health field, while the social security field is primarily organised around the interests of the state alone (although professionals – e.g. third sector actors – and market actors can and do play a role, this is not typically in any sense related to processes of accountability or governance). This difference in the relative power of the state means service users have varying degrees of power too. Patients have traditionally played a crucial role in the struggle between medical professionals and the state, who are frequently vying for power and resources from each other. As such, patients are often interpolated into ongoing countervailing struggles between different actors (see Speed and Gabe, 2019), e.g. the state has used patients to mobilise attempts to strip autonomy and

power away from doctors (i.e. a buyers' revolt, Light, 2010). Similarly, professionals have used patients to call on the state to provide more funding for services. Patients, then, have often been able to use these countervailing forces to increase their influence so that they are not just pawns of these other actors. The ambiguity of the structural location of patients means that they are subject to multiple, competing logics of difference and equivalence, with various groups seeking to ally or disavow them and to utilise them to help define who is the 'equivalent other'.

Out-of-work beneficiaries of means-tested social security, by contrast, are structurally far weaker in the social security field because the state is, broadly speaking, the only major player in that field. There is, quite simply, no equivalent countervailing force (i.e. the medical profession) in the social security space against which the state positions itself. This is not to suggest that there are no countervailing forces in the social security field at all. There are social workers, third sector organisations, charitable trusts, and even some professional lobby groups that are all active in trying to speak on behalf of both social security beneficiaries and those who work in the sector. But their position in the field is quite different. If we consider the founding of the NHS, Nye Bevan famously said he needed to stuff the doctors 'mouths with gold' to get them to accept the NHS (Timmins, 2017: 115) because doctors were 'crucial to the whole enterprise' (Footnote cited in Timmins, 2017: 115). They were the *sine qua non* of the NHS. The social security field did not have an equivalent body that needed to be co-opted to create the welfare state. Of course, the creation of the welfare state did, over time, produce powerful vested interests with significant influence in shaping social security policy, but even these professional organisations still rely (directly or indirectly) on the government for funding. The expansion of the mixed economy (Hills, 2014) and the competitive commissioning processes that have underpinned that expansion have potentially reduced the independence of the third sector from the government by curtailing their capacity to be a critical voice (Macmillan and Paine, 2021). Indeed, by some accounts, even the influence of think tanks is largely determined by the content of their advice and so their influence will diminish if the policy ideas they seek to promulgate do not align with the government's priorities (Craft and Howlett, 2012). One possible implication of these structural positions within the field is that if third sector actors or think tanks align too closely with service users, they run the risk of being excluded through the same logic of equivalence which excludes social security recipients themselves. The problem in both cases is that, in this institutional configuration, more user involvement would only serve to weaken the state's position vis-à-vis those on social security and these other actors. As such the imperative to address the democratic deficit in this field is weak. In fact, it may be in the states' interest to increase this deficit. This lack of a countervailing force capable of mobilising a sufficient counter logic of equivalence may go some of the way to explaining why the participatory imperative is so underdeveloped in context of social security.

Second, market actors play quite different roles in both spaces. The relation of patients to market actors is unlike the relation of social security beneficiaries to market actors. The market for healthcare is (potentially at least) incredibly profitable and the entities that are most profitable are those which provide life enhancing treatments. Innovation is led by the affluent – that is, by providing treatments to ailments that afflict the well-heeled – and by the medicalization of existing

problems. These market actors, such as pharmaceutical companies, will often use patients to put pressure on both states (lobbying) and professionals (advertising) to ensure their products are prescribed to patients. There is often money to be made from listening to the preferences of (at least some) patients.

However, in the context of means-tested social security for out-of-work beneficiaries, poverty can be extremely profitable. The entities that are most profitable, however, are those which exploit the impoverished and deepen their precariousness. Note the contradiction, healthcare development is driven by targeting the affluent, whereas social security development targets the poor. In the UK, for example, the outsourcing of welfare-to-work schemes to private entities such as G4S, ESG, and Serco created substantial profits for firms ostensibly helping people to get off welfare and into work (Foster et al., 2014). Some of the owners of these organisations have been generous donors to the Conservative Party and long-term advisers to a number of senior Conservative politicians, including George Osborne, David Davis, and Iain Duncan Smith (the architect of the Work Programme) (Syal and Hughes, 2012). Things are opaque in the British political system about who lobbies the UK government and how much; but we know that many of these companies have been actively lobbying governments in other countries (such as the US). Indeed, these organisations may have lobbied the UK government to introduce, expand or maintain these training programmes and so, to the extent that out-of-work claimants want such support, these companies may have formed a potential, powerful alliance with out-of-work social security beneficiaries in relation to the government. However, this is not a relation of solidarity in part because these Work Programme providers have proven to be largely ineffective but also because these providers created hardship through their aggressive use of sanctions (Patrick, 2017). As a result, this lobbying operates as a logic of difference, one which functions in the long term to protect the status quo and maintain impoverishment and precarity, whilst appearing to appeal against those very things. In this case, profits flow from managing and entrapping the poor.

These two differences around power and positioning across the two fields actively contribute to the creation of barriers to including lived experience in social security space. The dominance of the state in the social security field, particularly in the UK, combined with structurally weaker professionals means there is little pressure on government to incorporate these voices into decision making processes. Those actors (such as academics and think tanks) which are calling for social security recipients to be incorporated often have more marginal positions within the field, and have less power than the state in determining policy decisions and how decision-making processes are organised. Their marginality means they struggle to reconfigure the logics of difference and equivalence which currently dominate the social security space. The health field is different. Professional bodies are not only more powerful in the health field but they are also more patient-directed than professionals in the social security field. Professionals then have the opportunity to become more effective advocates for patients than social security professionals in the social security field. We turn now to consider what this might suggest about the relation between beneficiaries of social security and the state, and the way that these different service users are conceptualised by the state.

Ideological embedding of different narratives of service users

There does not seem to be a strong *a priori* reason why out-of-work beneficiaries of means-tested social security should necessarily occupy a structurally weaker position vis-à-vis the state in matters of social security policymaking. Rather, in our view, this configuration is the product of political choices that are rooted in prevailing ideological considerations of the form of social security, and is largely reflected in the state's desire to pursue their goals unencumbered from the interests of social security beneficiaries. The shifting position of patients in relation to the NHS (as one manifestation of state power) over the last 70 years illustrates the potential malleability of the positions of these actors in their various fields of power. It is not enough, therefore, to merely describe the location of out-of-work beneficiaries of means-tested social security in their respective fields, we must also interrogate how the abjection of lived experience in social security policymaking is constructed, legitimated, and maintained. Here, again, the logics of difference and equivalence which circulate patients and social security beneficiaries can help us illuminate how this occurs.

Our claim is that the institutional configurations which marginalise the voices of the beneficiaries of social security and which incorporate the voices of patients are 'ideationally embedded' (Somers and Block, 2005) by different social imaginaries of who social security beneficiaries are and who patients are. The ideational embeddedness of institutions is the recognition that ideas and public narratives construct and normalize organizational forms and in so doing create symbolic divisions within a field. Crucially, for Somers and Block, not all ideas are created equal, some ideas hold a certain comparative advantage within the epistemic terrain that currently organises specific social forms. This means that some logics of difference and equivalence fit more easily with each other and with existing institutions, potentially reflecting the ongoing struggles for hegemony within any given field.

For example, the location of patients in relation to the NHS (state) and medical professionals is ideationally embedded in notions of care (Friese, 2019). This is helpful because others have argued that the democratic deficit and the lack of participatory forms of decision-making are connected to the state's sequestering of care (Heier, 2020; Tronto, 2013). Now, what care is (or might be) is not a stable construct, and it has been theorised in a variety of ways and settings, but we argue that the concept of care which organises doctor-patient relationships is primarily concerned with 'caring for' (Schrader, 2015), which is a goal-directed act (good health) performed on behalf of someone who lacks the ability or autonomy to perform this act themselves. There is a great deal of scope within this broad notion of 'caring for' to conceptualise what care means in an organizational or institutional sense. What is perhaps more important for our purposes is that this ideational embedding of patients in the explanatory framework of care – that is, 'caring for' is how we make sense of what is happening in healthcare provision – makes certain logics of difference and equivalence more or less available to us. This is because deservingness is already inscribed in the notion of 'caring for' which permeates the doctor-patient relation (Fahy and Smith, 1999) – that is, patients are patients because they are vulnerable and lack the ability or autonomy to perform a certain action on their own behalf. The logic holds that patients are patients because they need and deserve care. This does not mean to say that all patients receive care – rather, our point is that in the public

imaginary, the position that all patients who need care should receive care is a strong (hegemonic) position, much more so than notion of people needing social welfare.

As such, the location of out-of-work beneficiaries of means-tested social security in relation to the state is different and is embedded in notions of active citizenship, rather than notions of care. The state is not seen to be ‘caring for’ beneficiaries when it provides them social security. Moreover, the state is not performing some goal-directed act which recipients cannot perform for themselves. Unlike patients, social security beneficiaries are perceived as being able to help themselves. This key difference means the social rights associated with citizenship are predicated on adopting certain kinds of behaviour. Ideationally embedding social security beneficiaries in notions of active citizenship therefore is part of the logic of difference which maintains existing institutional and symbolic structures within these fields, which consequentially operate to marginalise the lived experience of beneficiaries. This explanatory framework assumes the primacy of state power over the conditions of social rights and therefore undermines, indeed obviates, any claim on the state to heed the preferences of beneficiaries. This is not to say that the state-claimant relation could not be re-embedded in the explanatory framework of care: indeed, many argue that this is precisely the kind of shift that needs to occur in how the state sees beneficiaries – see Fraser (2003) or Patrick (2017). Others have argued that care needs to become more central to how states function as a whole (Tronto, 2013). We argue, however, that this shift is unlikely without a concomitant shift in the relation between social security beneficiaries and the state. To return to Dean (2017) this might be evidenced in terms of the articulation of opportunities for genuine participation in social security policy contexts. Currently, the ideational embedding of beneficiaries as active citizens works positively in the state’s interest, functioning to limit and constrain access to social security. Dislodging the dominant logics of social security becomes difficult without also changing the institutions that are sustained by those ideas.

This is not to imply that such change is impossible, however. Indeed, one leverage point around which these public narratives of both beneficiaries and patients seem to coalesce is around notions of deservingness, which, as we have argued, are embedded in conceptions of care (Tronto, 2013). Both care and deservingness are fundamentally shaped by how the beneficiaries of state provision are framed in terms of desert: the patient’s deservingness is a ‘caring for’ role, predicated on a lack of autonomy while the claimant’s deservingness is an ‘active citizenship’ role in which they (are expected to) assert their autonomy. The difference is in how these relations of deservingness get embedded and how they are reconstituted through particular institutional forms. Again, these relations are not forever fixed and could change in the future. The question becomes one of how best to initiate these types of changes. This brings us to the third strand of our argument which is concerned with redressing the stigma around social security.

Out-of-work social security and the political economy of stigma

The differences in the ideational embedding of patients and out-of-work beneficiaries of means-tested social security – and the consequent logic of difference which

flows from it – can generate stigmatised identities. To analyse how stigma contributes to the elision of lived experience in social security policymaking we draw on the approach described by Tyler (2020), who argues that analyses of stigma should examine where it is produced, by whom and for what purposes. This also raises structural questions about whether and how those who are stigmatised can actively seek to reclaim those spoiled identities and turn them into positive identities around which collective forms of action and resistance can mobilise.

We start with considering patients precisely because they have been successful at reclaiming previously stigmatised identities and then forging collective action around those reclaimed identities to make claims on the state. Examples include the HIV/Aids movement (Maguire et al., 2004), the Breast Cancer movement (Mukherjee, 2011), and more recently the mental health movement (Taggart and Speed, 2019). These were not uncontested (nor unalloyed) successes but these have all been able to resist and remake the processes of stigma production whilst also making claims on the state for more resources. These instances all illuminate how the processes of stigma production (often state-sanctioned) have generated the conditions for their resistance.

If anything, the opposite is true of out-of-work beneficiaries of means-tested social security, as social security stigma seems to have become increasingly residualised over time. This stigmatisation of beneficiaries is, in some ways, unsurprising because the deployment of stigma cannot be disentangled from capitalist incentives (Tyler, 2020). Unlike health and illness, social security stigma serves as a form of social control to produce active citizens which are aligned with capitalist values. This can be discerned in the founding logic of the social security state, which was to view poor relief as shameful (Somers and Block, 2005). The logic of capitalism resists efforts to reclaim the identities of social security beneficiaries and forge coalitions because to do so would require the valorisation of ‘dependent poverty’, which is antithetical to the disciplined and productive subject of capitalism (Tyler, 2020). Within the hegemony of capitalism, it is unclear whether receiving social security can ever be anything other than a spoiled identity.

But, our claim in this section goes further. We argue that there is fundamental paradox at the heart of social security which constrains resistance, and that this has been compounded by policy changes which have undermined the capacity for resistance among those deeply affected by the residualisation of social security. On the one hand, the stigmatisation of social security beneficiaries is rooted in notions of dependent poverty due to lower work effort. Conversely, the available evidence suggests that the vast majority of social security beneficiaries only receive support for a short period of time (Hills, 2014). The actual experience of being a claimant is completely divorced from this caricature of the work-shy, long-term claimant; and yet this characterisation continues to dominate the social rationality of social security policy. Moreover, the identity of claimants is so transitory for most people that it is simply rather unlikely to become a durable marker of their sense of self (Lister, 2015). In contrast, the most effective organising around health-related stigma has been around chronic conditions in which the ‘spoiled identity’ is durable in a way that creates a shared experience among otherwise disparate groups. In fact, the socio-demographic randomness of much chronic illness means that it tends to affect people across all ranges of income, class, ethnic and gender divisions, and it is

precisely this heterogeneity that makes these groups effective at mobilising for change. In other words, the stigmatisation of beneficiaries as dependent is less likely to be resisted precisely because so few people (proportionately, and at any one specific time) are actually dependent on social security – and, for those that are, this is likely to be far more transitory than it is for people with a chronic illness.

There is, however, another reason why resisting these stigmatising explanatory frameworks of beneficiaries is difficult. The history of social movements suggests that successful resistance is most often formed when a shared economic situation forges a status group (Barnes, 1995). In our view, policy changes in recent years have actually made it harder to forge this kind of status group and have therefore made it more difficult to create successful resistance. In other words, the activation model of social security has become so all-consuming under Universal Credit that it has undermined the space for resistance while austerity and the digitalisation of social security have also stripped away the sites around which such resistance could form. This comes through clearly in Koch and Reeves' (2021) work on Universal Credit where one interviewee – who was also an activist – noted that she had to be 'careful' because she feared activism might lead to a sanction. It was not always like this, she reminisced, 'Back in the 1990s, you could be on the dole and use your benefits money to do political activism, but today you can't do that, you cannot do that anymore. Activism is now a privilege of the middle classes'. On top of this, the locations at which beneficiaries could meet, including Jobcentres or perhaps even foodbanks, are deeply stigmatised spaces where many people experience a sense of shame. These feelings can exacerbate social exclusion and undermine the sense of shared experience.

In fact, this stigmatisation of social security is so deeply embedded in the Anglophone world that even those in poverty often deploy such images and tropes (Shildrick and MacDonald, 2013) and it is this internal boundary drawing between those who share similar economic positions that 'impedes solidarity and collective resistance' (Lister, 2015). These distinctions are another example of a logic of difference which is maintaining existing structures (Glynos and Howarth, 2007) by actively breaking down the material equivalences within these groups, such that people are not united in opposition to a hostile other (in this case the conditional, sanctioning state). Furthermore, an emphasis is placed on policies developed with the intention of undermining any 'challenges to the status quo' and this tends to be accomplished 'by addressing some (or all) of the concerns expressed by various groups or subjects, thereby preventing the linking together of demands' (*ibid* p.321).

Viewed together, it seems that social security beneficiaries face considerable difficulties in building movements which might reclaim this spoiled identity in part because the durability of social security stigma is a product of both the particular relations of the stigmatised to those social security identities and the political economy of capitalism (Tyler, 2020). Being a social security beneficiary is frequently so transitory that most people never seek to reclaim and resist that identity. For those in whom this identity does persist, there are other structural barriers that make resistance challenging (Lister, 2015). This configuration of stigmatised identities combined with the atomisation of beneficiaries, both of which are situated against the background of the cultural political economy of capitalism, in part, explains why beneficiaries themselves have been generally unable to mobilise to challenge their exclusion from the policymaking process.

Conclusion

This leaves us asking a question about how best out-of-work beneficiaries of means-tested social security might build a movement/coalition which could effectively challenge this prevailing democratic deficit. There is a strong normative imperative to involve users in the production of social security policy (just as they are in health policy), but the prevailing institutional setting (a participatory regime predicated on the practices of ‘arbitration and oversight’) mitigates against this (Dean, 2017). As such, we rather pessimistically conclude that the democratic deficit in social security policy will likely continue and the tragic consequences of social security reform in recent years will continue to be repeated.

There is, of course, the possibility that these fields change. As already mentioned, the social movement around HIV provides an example of a ‘spoiled identity’ which has been reclaimed and used to obtain positive recognition (Maguire et al., 2004), remaking the structure of symbolic divisions in a given field. But, it is unclear whether this kind of bottom-up articulation of demands can work in the context of a broader structural constraint to including these voices into policymaking. There is a clear need for the structural recognition of the rights of social security beneficiaries and the subsequent application of those rights to the ongoing operation and development of social security policy. Accomplishing this will require whole-scale changes in how the person claiming benefits is regarded by those others inside and outside of the social security system. Hegemonic, negative views of social security beneficiaries perpetuate logics of equivalence and difference which prevent the formation of broader alliances. If real change is to be effected, and if social security beneficiaries are to be involved in tackling the democratic deficit in social security policy and practice, it seems that the best place to contribute is in helping develop a national, grassroots social security policy movement.

Activists and researchers have been driving this agenda forward, and some have been successful at making in-roads. For example, a research project called Covid Realities has examined the lived experience of parents and carers on low incomes during the pandemic (Patrick et al., 2021). They have been successful at informing the national conversation about these reforms. Their participants have been featured on national radio and given evidence to government select committees. Similarly, Poverty Truth Commissions have been set up in various parts of the country and have had relative success at challenging the ideological and stigmatising views of social security beneficiaries. The Joseph Rowntree Foundation, Thrive Teeside, and Poverty2Solutions have all also emphasised participation in their work. There are even some instances of change at statutory level – for example, see the new Social Security Scotland Agency developed by the Scottish Government, which includes ‘user experience’ panels. Whilst those most stigmatised are not covered (i.e. the unemployed) by the new agency, it does point towards the possibility of political change in this field. Such efforts are welcome and their success shows there is both appetite and scope to more formally incorporate lived experience into how central government conduct policymaking in this area.

The three issues we describe in this paper all overlap, creating a stigmatised and structurally marginalised service user position located within a field dominated by powerful and largely unaccountable state actors. The toxicity of this service user

identity is especially evident when viewed in relation to the similar but distinct service user identity experienced by those using the NHS. Together, these issues engender a broader but still stigmatising political economy of social security, such that those who stand the most to gain from organising around these identities face substantial barriers to building communities of solidarity. This is because being an out-of-work beneficiary of means-tested social security becomes a negative social space that few people want to occupy or to identify with. The analysis we present in this paper outlines some of the social processes that generate these exclusions. It is our intention that in so doing we might take some steps to reclaiming social welfare as something which is positive and good, which can be used as a means of directly helping people who need support. Social welfare should be seen as an opportunity to lessen the social reproduction of inequality and disadvantage. To borrow from Fraser (2003), this positive reclamation of social security would foster a broader re-embedding of the politics of redistribution, whereby all forms of inequality might be reduced by social policies which seek to lessen the widening inequalities in the UK. An essential stage in reclaiming the spoiled identity of the welfare recipient would be in finding meaningful ways in which people might be invited to participate in welfare policymaking.

Acknowledgements. Both authors would like to acknowledge the contribution of Ruth Patrick with comments on an initial draft. Aaron Reeves acknowledges funding from the Nuffield Foundation. The Nuffield Foundation is an independent charitable trust with a mission to advance social well-being. It funds research that informs social policy, primarily in Education, Welfare, and Justice. It also funds student programmes that provide opportunities for young people to develop skills in quantitative and scientific methods. The Nuffield Foundation is the founder and co-funder of the Nuffield Council on Bioethics and the Ada Lovelace Institute. The Foundation has funded this project, but the views expressed are those of the authors and not necessarily the Foundation. Visit www.nuffieldfoundation.org.

Competing interests. The authors declare none.

Note

1 The conceptual value of 'lived experience' has been contested in part because all experience is necessarily lived. Following McIntosh and Wright's (2019) paper, we use 'lived experience' as 'a shorthand' for a 'stand-point critique' which grants 'respect and esteem' to marginalised communities. Crucially, the 'lived' part of this phrase is trying to capture the shared 'structures of feeling' that are typical of a particular group rather than the experience of a specific individual. Discursively, 'lived experience' is intended to confer counter-legitimacy to people who find themselves undermined by 'professional experience'.

References

- Barnes, B. (1995), *The Elements Of Social Theory*. London: Routledge.
- Beresford, P. and Croft, S. (2016), *Citizen Involvement: A Practical Guide for Change*. Macmillan International Higher Education.
- Boote, J., Wong, R. and Booth, A. (2015), 'Talking the talk or walking the walk?' A bibliometric review of the literature on public involvement in health research published between 1995 and 2009. *Health Expectations* 18(1): 44–57.
- Bourdieu, P. (1979), *Outline of a Theory of Practice*. Cambridge University Press.
- Craft, J. and Howlett, M. (2012), Policy formulation, governance shifts and policy influence: location and content in policy advisory systems. *Journal of Public Policy* 32(2). Cambridge University Press: 79–98. DOI: [10.1017/S0143814X12000049](https://doi.org/10.1017/S0143814X12000049).

- Dean, R.J.** (2017), Beyond radicalism and resignation: the competing logics for public participation in policy decisions. *Policy & Politics* 45(2). Policy Press: 213–230.
- De Cleen, B., Glynos, J. and Mondon, A.** (2018), Critical research on populism: Nine rules of engagement, *Organization*, 25(5), 649–661.
- Fahy, K. and Smith, P.** (1999), From the Sick Role to Subject Positions: A New Approach to the Medical Encounter. *Health* 3(1). SAGE Publications Ltd: 71–94.
- Fligstein, N. and McAdam, D.** (2011), Toward a General Theory of Strategic Action Fields. *Sociological Theory* 29(1): 1–26.
- Foster, S., Metcalf, H., Purvis, A., Lanceley, L., Foster, R., Lane, P., Tufekci, L., Rolfe, H., Newton, B., Bertram, C. and Garlick, M.** (2014), *Work Programme Evaluation: Operation of the Commissioning Model, Finance and Programme Delivery*. Department for Work and Pensions London.
- Fraser, N.** (2003), Social Justice in the Age of Identity Politics: Redistribution, Recognition and Participation. In: N. Fraser and A. Honneth, (Eds.), *Redistribution or Recognition?: A Political-Philosophical Exchange*. London:Verso, pp. 7–109.
- Friese, C.** (2019), Intimate entanglements in the animal house: Caring for and about mice. *The Sociological Review* 67(2): 287–298.
- Glynos, J. and Howarth, D.** (2007), *Logics of Critical Explanation in Social and Political Theory*. Abingdon: Routledge.
- Heier, J.** (2020), Democratic Inclusion Through Caring Together with Others. In: P. Urban and L. Ward (Eds.), *Care Ethics, Democratic Citizenship and the State*. International Political Theory. Cham: Springer International Publishing, pp. 53–76.
- Hills, J.** (2014), *Good Times, Bad Times: The Welfare Myth of Them and Us*. Bristol: Policy Press.
- Howarth, D.** (2010), Power, discourse and policy: articulating a hegemony approach to critical policy studies. *Critical Policy Studies*, 3(3-4), 309–335.
- Koch, I. and Reeves, A.** (2021), From social security to state-sanctioned insecurity: How welfare reform mimics the commodification of labour through greater state intervention. *Economy and Society* 50(3). Routledge: 448–470.
- Krause, M.** (2017), The Patterns in Between: “Field” as a Conceptual Variable. In: C. E. Benzecry, M. Krause and I. A. Reed (Eds.), *Social Theory Now*. Chicago, IL: University of Chicago Press.
- Laclau, E.** (1996), *Emancipation(s)*. Verso.
- Light, D.W.** (2010), Health-care professions, markets and countervailing powers. *Handbook of medical sociology* 6: 270–289.
- Lister, R.** (2015), ‘To count for nothing’: Poverty beyond the statistics. *Journal of the British Academy* 3: 139–165.
- Macmillan, R. and Paine, A.E.** (2021), The third sector in a strategically selective landscape – the case of commissioning public services. *Journal of Social Policy* 50(3). Cambridge University Press: 606–626. DOI: [10.1017/S0047279420000355](https://doi.org/10.1017/S0047279420000355).
- Madden, M. and Speed, E.** (2017), Beware Zombies and Unicorns: Toward Critical Patient and Public Involvement in Health Research in a Neoliberal Context. *Frontiers in Sociology* 2: 7. DOI: [10.3389/fsoc.2017.00007](https://doi.org/10.3389/fsoc.2017.00007).
- Maguire, S., Hardy, C. and Lawrence, T.B.** (2004), Institutional entrepreneurship in emerging fields: HIV/AIDS treatment advocacy in Canada. *Academy of management journal* 47(5): 657–679.
- Martin, J.L.** (2003), What Is Field Theory? *American Journal of Sociology* 109(1): 1–49.
- Mcintosh, I. and Wright, S.** (2019), Exploring what the Notion of ‘Lived Experience’ Offers for Social Policy Analysis. *Journal of Social Policy* 48(3). Cambridge University Press: 449–467.
- Mehta, J., Taggart, D., Clifford, E. and Speed, E.** (2021), “They say jump, we say how high?” conditionality, sanctioning and incentivising disabled people into the UK labour market. *Disability & Society* 36(5). Routledge: 681–701.
- Moreau, J.T. and Rudge, T.** (2019), How “care values” as discursive practices effect the ethics of a care-setting. *Journal of Organizational Ethnography* 8(3): 298–311. DOI: [10.1108/JOE-04-2018-0024](https://doi.org/10.1108/JOE-04-2018-0024).
- Mukherjee, S.** (2011), *The Emperor of All Maladies: A Biography of Cancer*. 1st edition. London: Fourth Estate Ltd.
- O’Shea, A., Chambers, M. and Boaz, A.** (2017), Whose voices? Patient and public involvement in clinical commissioning. *Health Expectations* 20(3). Wiley Online Library: 484–494.
- Patrick, R.** (2017), *For Whose Benefit?: The Everyday Realities of Welfare Reform*. 1 edition. Policy Press.

- Patrick, R. and Reeves, A.** (2020), The legacy of an ideology: a decade on from benefits as lifestyle choice. *European Journal of Public Health* (ckaa215).
- Patrick, R., Garthwaite, K. and Power, M.** (2021), Covid Realities. Available at: <https://covidrealities.org/> (accessed 26 February 2021).
- Phelan, S.** (2011), The Media as the Neoliberalized Sediment: Articulating Laclau's Discourse Theory with Bourdieu's Field Theory. In: L. Dahlberg and S. Phelan (eds), *Discourse Theory and Critical Media Politics*. London: Palgrave Macmillan UK, pp. 128–153.
- Russell, J., Fudge, N. and Greenhalgh, T.** (2020), The impact of public involvement in health research: what are we measuring? Why are we measuring it? Should we stop measuring it? *Research Involvement and Engagement* 6(1): 63.
- Schrader, A.** (2015), Abyssal intimacies and temporalities of care: How (not), to care about deformed leaf bugs in the aftermath of Chernobyl. *Social Studies of Science* 45(5): 665–690.
- Shildrick, T. and MacDonald, R.** (2013), Poverty talk: how people experiencing poverty deny their poverty and why they blame 'the poor'. *The Sociological Review* 61(2): 285–303.
- Somers, M.R. and Block, F.** (2005), From Poverty to Perversity: Ideas, Markets, and Institutions over 200 Years of Welfare Debate. *American Sociological Review* 70(2): 260–287.
- Speed, E. and Gabe, J.** (2019), The reform of the English National Health Service: professional dominance, countervailing powers and the buyers' revolt. *Social Theory & Health*. DOI: 10.1057/s41285-019-00116-x.
- Speed, E., McPherson, S. and Beresford, P.** (2020), Questioning the patient participation imperative. In: I Boncori and T Loughran (Eds.), *Health and Wellbeing - The University of Essex Reader*. Naples: Editoriale Scientifica, pp. 169–186.
- Syal, R. and Hughes, S.** (2012), Firm established by two Tory donors made millions from work schemes. *The Guardian*, 29 July. Available at: <https://www.theguardian.com/politics/2012/jul/29/sovereign-capital-tory-donors-millions> (accessed 9 September 2022).
- Taggart, D. and Speed, E.** (2019), Stigma and Mental Health: Exploring Potential Models to Enhance Opportunities for a Parity of Participation. *Journal of Ethics in Mental Health* 10(VI): 1–19.
- Timmins, N.** (2017), *The Five Giants: A Biography of the Welfare State*. Revised edition edition. London: HarperCollins.
- Tronto, J.C.** (2013), *Caring Democracy: Markets, Equality, and Justice*. New York: NYU Press.
- Tyler, I.** (2020), *Stigma: The Machinery of Inequality*. London: Zed Books Ltd.