RESEARCH

Adverse Effects of Social Security on Disabled People and Their Families in the UK: Iatrogenic Outcomes of Quasi-Clinical Administration

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In the aftermath of the 2008 financial crisis many countries embarked on a prolonged period of public sector 'austerity' which for some included seeking dramatic reductions in social security spending. It is in this context that the research investigates the negative impacts of interactions with the UK disability benefits system on the lives of disabled people. The research uses in-depth semi-structured interviews and a focus group to study the experiences of 49 people who either had an impairment or chronic health concern and/or were family carers for an adult or child with these concerns. The analysis identified four aggregate dimensions evidenced by the transcript data: harmful health and well-being consequences, negative financial and resource impacts, perverse employment effects and wider social disability concerns. These dimensions highlight how interactions with 'social security' policy in the contemporary context can have harmful, iatrogenic consequences for disabled people and their families.

Introduction

This study investigates how the lives of disabled people have been impacted by their interactions with the UK social security system. Negative impacts are a concern for disabled people and campaigning organisations in the context of the so-called 'austerity' policy agenda associated with the contraction of state support. 'Austerity', a neo-liberal political response to the 2008 financial crisis, led the UK and other countries, including Estonia, Ireland, Hungary, Greece, Germany and Canada, to dramatically reduce their spending on welfare. Across the OECD countries, the slowdown in social spending hit disability and sickness benefits and labour market related benefits and policies hardest (OECD, 2016); between 2009 and 2013 spending on disability and sickness benefits as a percentage of GDP fell by 5.2 percent across the OECD and by 3.4 percent in the UK (OECD, 2018).

In the UK, these public spending cuts are associated with wider social security 'welfare reforms' which have redrawn the boundaries of eligibility for disability-related and other social benefits (Roulstone 2015). The restriction of access to support (benefits and/or services) is coupled with an increased articulation of notions of deservingness, particularly linking disability to 'vulnerability' with the implications a continual theme within social policy research e.g. in relation to stigma and identity (Brown 2012). Our understanding of how economic austerity and recent social security reforms (and rhetoric) are impacting the lives of disabled people and their families is growing. Interviews with recipients of long-term sickness benefits have also identified that, whilst some people may not feel stigmatised as applicants, others may be deterred from making claims for fear of being positioned as 'undeserving' as a result of contemporary discourse and administrative processes (Garthwaite 2011, 2014). 'Reform' then, impacts on disabled people whether or not they are applicants for disability specific benefits, particularly given increased conditionality. The Work Capability Assessment has specifically been associated with increased mental distress including suicides (Barr et al., 2016). Further evidence is available from campaigns by disability organisations (e.g. Disabled People Against Cuts) and research-focused campaign collectives (e.g. see 'Responsible Reform', known as the Spartacus Report by Diary of a Benefit Scrounger, Campbell et al., 2012). The recent report of the United Nations Committee report by the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD, 2017) also highlighted the negative consequences of austerity on disabled people and their families. This is the specific context for the experience of respondents in this study, with policy debate around more recent legislation part of the discourse landscape in which social security is delivered.

This study contributes to this emergent body of evidence by retaining a concern with individual impacts but also seeking to develop a relational context that brings the experience of disabled people and family members (including

carers) together. Through the contributions of the participants, the research documents how welfare reforms which have deepened the quasi-clinical administrative process, and interactions with the disability benefits system more generally, have adverse consequences for disabled people and their families.

Policy and Research Context

Increased recognition that disability is a contested category in both policy and research is our starting point for engaging with the implications of policy in a social and relational perspective. Historically, disability had often been assumed to be a 'non-problematic category for analytical purposes', with disability represented as an individual (rather than a social) outcome and as personal tragedy (Oliver, 1986: 6). More recently, contemporary social policy in the UK has been both strongly influenced by and critiqued through social model analyses provided from the disabled people's movement and allied academic study. These approaches emphasise social, material and interpersonal barriers to participation and foreground rights-based claims to social support. However, there is tension between the social model and more welfarist approaches. The former provides a "blueprint for more disability-led policy" that acknowledges disabled people as 'citizen experts' while the latter is associated with "increasingly hard rationing as to just who counts as disabled" (Roulstone & Prideaux 2012: 19).

Whilst social model approaches have been fundamental to critiques of policies and implementation, policy-influencers and politicians have recently tended to emphasise approaches which focus less on social aspects of disability. The most significant basis for this is a form of biopsychosocial model of disability which stresses biological and psychological (including behavioural) factors and downplays socio-economic elements. This model was particularly salient in discussions about Personal Independence Payment (PIP) in the 2012 Welfare Bill debates, demonstrated in the contribution by Lord Freud (2012) who argued that the social model was 'not the right way to go' and instead 'we have gone for the biopsychosocial model'. However, the notion of *the* Biopsychosocial model is misleading, with the originally named approach (Engel 1980) seeking to expand medical-based assessments of psychiatric support needs. Later developments, including the World Health Organisation International Classification of Functioning, Disability and Health, have been applied more widely (Wade & Halligan 2017). A particular UK development, the 'Waddell-Aylward Biopsychosocial Model,' to which Lord Freud referred, has been influential in UK Policy development over the past decade and has been critiqued as too reductionist and overly-responsibilising i.e. victim-blaming (Shakespeare, Watson & Alghaib 2017).

These tensions in policy responses to disability extend into wider conceptualisations of social relationships and productive roles. This is evident in the way paid work has become an integral part of how disability and long-standing ill-health is conceptualised in Britain. This is clearly seen in relation to Employment Support Allowance (ESA), claimed by 1.17 million people aged 16–69 (Office for National Statistics (ONS), 2017). ESA claimants are placed in the Support Group (SG; not required to look for/engage in paid work) or the Work Related Activity Group (WRAG; required to participate in work related activities). Access to ESA and allocation to categories is managed through the Work Capability Assessment (WCA) which has been represented as a form of 'social sorting' based on individualised understanding of disability but with social and economic consequences (Grover & Piggott 2010).

Current policy alignment with biopsychosocial inspired assessment has fostered the previously identified administrative approach to disability policy in the UK (Finkelstein 1991), in which clinical and social security processes have become messily entangled. This, today, can be said to be a quasi-clinical framework, whereby rigid assessments are administered by any one of a range of health professionals (employed by for-profit private companies) to determine social security entitlements (and restrict access to these). In this context, and as argued by Stone (1985) from the USA context, disability can be understood as an administrative category which serves the political imperative to reconcile distributive systems of work and need (i.e. preserving the economic system that gives primacy to individual paid labour). This recognition of the political purpose of quasi-clinical administration suggests that insights from medical sociology are relevant for disability policy and research: in particular, the lens of iatrogenesis can be used, as in this study, to examine adverse effects of benefit policy regimes on the lives of disabled people. Iatrogenesis was first discussed in relation to health care interventions, systems and policy where iatrogenic damages are embedded (Illich 2003). These damages can 'restrict the vital autonomy of people by undermining their competence in growing up, caring, ageing' or by nullifying 'the personal challenge arising from their pain, disability, and anguish' (Illich 2003: 921). While Illich's concerns were directed to the medical establishment and professions, and he refers to individual competences rather than social marginalisation or exclusion, the scope of his critique has been usefully extended (including to juvenile justice systems, Barton, 2016). Kennedy (2017) asserted that potential iatrogenic risks to physical, psychological and social health may lead people to *reduce* engagement with health professionals. McKnight (1989) has highlighted iatrogenic effects of social services in modern welfare states by, for example, 'promoting' dependency. The eliciting of mental distress by contemporary social security and the individual pathologisation of socially induced distress as 'mental illness' (Thomas et al., 2018) is a fundamental context for this study.

Another feature of biopsychosocial models of disability is that they tend to downplay interdependencies in the lives of disabled people, but in reality, adulthood experiences of impairment and disability depend on personal, family and social relations. Some disabled people are themselves family carers and so may face social and economic marginalisation as well as incurring personal impacts of caring (Al-Janabi et al., 2016; Carers UK 2014). Addressing these relational

interdependencies in individual lives suggests that disability research and policy would benefit from a more family orientated approach whilst retaining disabled people's experience at the centre (Clarke 2010). This research responds by including disabled people and family members providing care as participants.

Methodology

Semi-structured interviews with 41 individuals and a focus group with eight other participants were conducted by two of the research team. Participants were members of families where at least one family member had recently been eligible or had applied for Disability Living Allowance (DLA), ESA or PIP (the replacement for DLA). Individuals identified as either the person who had made the claim or as another family member who was in most cases the main carer for the disabled person. Up to two family members in a family unit were interviewed: either the disabled family member and/or the person who identified as their 'main' carer and/or another adult family carer. Fourteen sample members participated as paired family dyads. The total sample size (n = 49) is in line with guidance in Saunders and Townsend (2016). The sub-sample sizes of those identifying as with a disability (n = 28) or as carers (n = 21) are also consistent with recommendations in Marshall et al. (2013).

The sample were recruited using different methods including a project website, contacts with disability and carer support groups, social media including Twitter, contacts with social work training programmes and snowballing. The website and information sheets given to contacts emphasised receipt of disability benefits (specifically DLA, ESA and PIP) and/or experiences applying for these benefits as a reason to participate in the research. The different methods of recruitment enabled us to achieve diversity within the sample in terms of impairment and family caring roles as well as representation from different regional locations in England, Wales and Scotland.

The sample of people with an impairment and people identifying as carers includes five participants who initially identified as disabled people and were also caring and two participants who initially identified as carers who also claimed a disability related benefit for themselves. A wide range of physical and mental health impairments and neurodiversity are represented. Participants in a caring role include those caring for young and adult children, grandchildren, spouses and parents. All participants are adults, the youngest is 18 and the oldest over 70. Thirty-five are female. See Supplementary Table A1 for details of sample characteristics including condition (of the individual and/or the person cared for) and family relationships (where relevant).

The interviews were conducted either face-to-face at a location of the participant's choosing, by phone or videoconferencing software (according to individual preference). The focus group was conducted at a social gathering of a group to which the participants belonged. We used a loosely structured protocol to encourage participants to talk openly and expansively about their disability and/or caring responsibilities, how these had impacted on their lives and their experiences of applying for disability benefits, for themselves or for another family member. There was also discussion of wider social and political issues around disability and welfare. The use of different data gathering methods enriched the data in a number of ways. First, the use of telephone/videoconferencing made it feasible to talk with people across the country. Second, while face-to-face interviews are often preferred in qualitative research because of the emphasis on personal aspects, we found that people were very forthcoming in phone/videoconferencing interviews, the greater anonymity provided by the physical separation of the interviewer and interviewee perhaps making it easier to discuss sensitive topics, as suggested by Vogl (2013). Thirdly, the focus group generated different kinds of information. For example, the extent to which problems and experiences were shared was highlighted although there was naturally less detailed discussion of personal concerns.

Ethical approval was granted by the Ethical Review Committee (ERN_14-0978). The participants gave informed consent for the interviews and focus group to be recorded. Recordings were transcribed verbatim. Pseudonyms are used to protect identities. Identifiable data were anonymised.

The detailed reading of the transcripts adopted a staged, inductive approach. This focused on themes evidenced through a staged and systematic ordering of the data (Gioia et al., 2012). The first stage of the analysis allocated multiple open codes to individual-level concepts. The second stage grouped similar codes within the data into conceptual, first order categories capturing participants' experiences. The third stage grouped the categories into a smaller number of descriptive, second-order themes. In the final stage of the analysis the coded extracts, grouped categories and themes were used to identify four overarching dimensions. To establish trustworthiness the initial coding and the development of grouped categories and aggregate dimensions were cross-checked between three research team members. Different interpretations were reconciled through discussion leading to some reconstruction of the themes. Figure A1 in the supplementary online data appendix summarises the data structure. QSR International's NVivo 11 software was used in support of this analysis.

Findings

The adverse impacts of interactions with the disability benefit system highlighted by participants identified health and wellbeing effects, financial and other resource problems, issues related to work and wider social disability concerns. These themes suggest a deeper and broader perspective on biopsychosocial thinking by integrating a more social element within the analysis. They also draw attention to temporal aspects of people's experiences.

Harmful health and wellbeing consequences

Health and wellbeing consequences of interactions with the social security system were linked to particular aspects including complexity and communication and specific processes such as assessments, appeals and reforms. Consequences spanned from emotional, mental and physical health impacts to fears and worries for oneself and others because of changes in policy and eligibility criteria limiting access to benefits.

The whole process of trying to claim benefits could be exhausting, with participants talking about despair and not being able to handle the stress: 'It was just too much to deal with. So, just everything I gave to my social worker and she made phone calls and did whatever. It did stress me out' (id29 Alison). In Alison's case, the wait to hear about the outcome of the claim was a particular source of stress: 'You know, that's stressful. When is it going to come? Is it coming?'

Particular processes were singled out as problematic. For example, many participants suffered distress because they were worried about or needed to appeal against a decision. Kay (id1) is a wheelchair user worried about having to reapply and perhaps appeal if her health deteriorates: 'I'd have to go through it all over again. Like the lady said, it's an extremely, extremely stressful situation. If I'm already in a stressed situation, could I cope with it?' She says that the process of being assessed is also 'degrading'. Alanna (id2) talked at length about the distress caused by the traumatic experience of an initial rejection for ESA and subsequent appeal: 'The whole thing was hideous… your life is hard enough already and now you're being told that you're not going to have any money… I was terrified that I was going to have to go through that whole process again.' Alanna goes on to explain that: 'For about two days beforehand, I just couldn't sleep, hardly ate, absolutely terrified of this. The stress of it was making my hair fall out. I'd had bald patches.'

For some participants the end result of the stress of engagement with the system was a serious mental health crisis. Penny (id11) said that she ended up with depression and Kay (id1) who is caring for a child with Asperger's said that negotiating the benefits system had made her very distressed: 'I nearly put the car through a brick wall and jumped out of the bedroom window last year.'

For family carers changes to benefit rules can also be traumatic, sometimes the last straw. As Wendy (id26) explains, rule changes put a lot of pressure on carers to keep up: 'They move the goalposts, they do something and then you feel so exhausted just trying to keep ahead of the game. You have to know about benefits, you have to know when everything's happening; we have to be like a brain surgeon.' The fear of losing benefits because of rule changes was common. The advent of PIP in particular seemed to be shrouded in doubt and uncertainty and participants worried that they or the person they provided support for could lose out. For example, Sarah (id4.1) believed that PIP had been introduced 'so less people can be entitled to it so that they can make a saving' and worried about how she and her son would cope if he was not awarded PIP: 'I'm thinking without that, what the heck are we going to do?' Wendy (id26) was also worried about having to reapply for benefits because of PIP: 'We had this form come and I thought, "Gasp". A carer and the disabled person always think straight away "They're going to take something from me". You never think that they're going to listen; you never think that it's going to go smooth.'

A commonly articulated concern on behalf of others was the possible chain of causality from benefits sanctions to ill-health. Christine (id28) believes that where people are moved off disability benefits in deprived areas this is 'self-perpetuating' because: 'It's just putting more and more stress and then suddenly you get all the mental health conditions that come as a result of long-term unemployment.' Similarly, Kattia (id12) has little faith in the system. She says 'It's bonkers,' that it may be true that 'We've got less people on benefits; we're saving money', but there are: 'people on disabilities claiming all sorts of, you know, having to go to shelters, having to go to food banks, having to go for extra support, going for more counselling, trying to commit suicide.'

Negative Financial and Resource Impacts

While disability benefits support disabled people and their families, changes to rules and regulations as well as procedural mistakes, mean that some people with a disability and their carers can lose out, leaving them insecure. This can happen for different reasons, including mix-ups due to lack of communication between different public offices. There are also additional, hidden costs associated with making claims. In consequence disabled people face financial struggles, worries and crises and there are also implications for carers.

Stuart (id27.2) is one of those who had his ESA benefits cut, and he and his partner, Hannah (id27.1), now find themselves in a difficult position, struggling to pay their bills: 'Just looking at what we've got each week to spend, it's come down from just under £200 a week to… It's going to be about £110 a week. It is not a lot. By the time we spend £65 on food and then sort of every two weeks we've got £35 gas and electric.'

Problems with payment also cause difficulties. PIP was awarded to Laura (id34.1) six-seven weeks after submitting her application, but because of a mix up the payment did not go into her account: 'Because in my head I were thinking have I spent it? I kept saying to [support worker], "Have I spent it?"' She says: 'Went to the bank didn't we, got the bank details and I hadn't spent it because it hadn't gone in.' The money had actually gone into an old account by mistake. Kattia (id12) reported how failure by benefit officials to process information she provided on her irregular work meant she bore the brunt of having to repay an 'overpayment.' 'That's not my fault and now I'm the one that has to deal with the consequences of that. I don't have the funds just to give you back that money.'

Over the longer term, as any assets that exist are eroded, disabled people may be struggling financially to meet financial needs, despite access to benefits. This situation is not helped by additional costs associated with making

a claim for benefit as articulated by Simon (id33) who says 'it's awkward now,' 'it's very hard,' because there are no 'drop-in' facilities or 'a free phone in the Benefits Agency anymore,' which means that claimants have to 'phone up and if you're on a pay-as-you-go tariff, you can see your credit sinking down like a bloody taxi thing, like a taxi meter.'

When benefits are restricted or denied this can even result in disabled people becoming homeless. This happened to Kattia (id12) who had difficulties accessing housing benefits: 'They would not fund over a certain amount of money a week per rent, which meant that that flat I couldn't take anymore. So I had to default on that flat and I had nowhere to go.' As a result she ended up staying on 'friends' floors.' She also lost out financially: 'I lost £250 because they wouldn't give me my deposit back, which I'd borrowed off my mum.' Kattia eventually ended up in a homeless hostel which was entirely inappropriate for her.

Participants also highlighted how the loss of DLA or ineligibility for PIP has knock-on effects for family carers since they automatically lose their entitlement to Carer's Allowance (currently worth £62.10 a week). This happened to Hannah (id27.1) who cares for Stuart (id27.2): 'It's awful because once his stops then my money stops as well and then you can't sign on because then they'll take it out of his money and then you're left with nothing to live on. It's crazy.'

Perverse Employment Effects and Incentives
The participants highlighted how benefit eligibility and payment rules can have unintended disincentivising effects that reduce the employment opportunities of disabled people and carers. These effects were associated with work-related risks of losing benefits and allowances and disabled people being pushed into the wrong kinds of jobs, both leading to 'false economies.'

These concerns are articulated by Daniel (id7.2), who had worked in the past, but is reluctant to take on another job because of the risk that the work will not last, or he will not be able to 'hold down' the job. He says this worry is 'constantly at the back of your mind.' He remembers that 'in the early 1990s, they, they said that, if you left your work voluntarily, you wouldn't get benefits. That was the worst thing they ever did for somebody like me because I would work for six months, save up a bit of money.' Daniel is clearly discouraged from trying to find work by these rules, he worries about taking on another job because of what would happen if he 'could only do it for six months.'

The eligibility criteria for Carer's Allowance also creates disincentives to work since the allowance is lost if a carer earns a penny more than the current lower net earnings limit of £110 a week. Emma (id32) couldn't claim Carer's Allowance when she was working as she earned marginally more than the earnings limit even though she only worked part-time: 'It's quite low and I think, I was calculated as being 90p over which meant that I couldn't get carers allowance at that time. For the sake of 90p I lost £200.' Jennie (id5) who has a disabled child said that she felt 'kind of trapped' because eligibility criteria made it difficult for her to take on paid work: 'We're kind of locked into a kind of a situation now where, because we're getting the money that we're getting, any work that I went and did if I got a part-time job, would only take us a little bit over what we're earning now.' These rules are a disincentive for carers who are not in employment to look for work and they may also deter carers from applying for the allowance.

Participants involved in voluntary work also worried that they might have to give up this work in order to maintain their access to benefits. For example, Karen (id3) had enjoyed doing voluntary work in the past, but had worried about losing her disability benefits as an advisor had told her: 'If it looks like paid work, you've got to either stop claiming the benefits, or stop doing the work.' This seems to be a short-sighted consequence of welfare policy focusing only on the financial benefits of work while ignoring the non-financial benefits that accrue to voluntary work as well as paid work. Participants talked, for example, about the confidence and self-respect they gained from volunteering.

Some benefit rules (and rule changes) can result in false economies: Kattia (id12) says that withdrawal of 'return to work schemes' was 'just ludicrous' and 'not going to help anything.' She says that: 'If anything, it's going to be more of a burden to the communities around because you're going to need to find more money to support them.' Furthermore, while welfare policy tends to focus on moving people into work to address poverty, work isn't always good for disabled people. As Kattia highlights, the wrong kind of work can impact negatively on their health: 'I have to think very carefully about what I can do that won't mess my body up even further, which isn't something that they look at when it comes to getting back to work and disability. They look at what you can actually do and that is it.' She worries that if her health deteriorates it will impact on the rest of her life and 'that is bonkers because realistically, if I can't support myself outside of that, I'm going to need more support.'

Wider social disability concerns
The benefit system is intended to address poverty, but because of challenges people face accessing the system and the social context in which it operates, some inequalities and disadvantages are exacerbated. This was compounded by a shared view that some aspects of the benefit system and the wider socio-political context 'demonised' disabled people and their families.

Accessing benefits can require determination and access to resources that are not available to everyone and, even when they are available, these resources can be stretched. Some people are therefore better positioned to meet these challenges and others are less fortunate, exacerbating inequalities and disadvantage. For example, Karen (id3) says that people with less confidence than herself have 'been turned down and given up' and goes on to contrast impacts of policy changes on the richest and the poorest: 'The bankers are getting away with millions and some piddly amount of

money that is being paid to disabled people is targeted.' Kattia (id12) agrees: 'It's definitely a keep the rich rich and the poor poorer sort of vibe at the moment.'

Increased inequality was also linked to reduced access to services. In this context, Simon (id33) talks about a drop in the number of day centres which he sees as a consequence of policy cuts: 'You know, it's just this redistribution of wealth, you know it's hitting everybody, all walks of life you know, except the rich, they're doing alright, bless them.' Simon (id33) believes that government cuts will make it harder for disabled people to access support and this will shift more caring responsibilities onto families. Here, Simon is holding the wider 'austerity' agenda responsible for day centre closures when these represent part of longer-term trend linked to personal budgets and a shift to more individual support (Pitt 2010).

While some participants did not experience particular difficulties accessing benefits, there was a view that the nature of a claimant's condition could be a determining factor. Claire (id23) thinks the move to PIP is 'a money-saving exercise' and will hit some harder than others, leading to more inequality: 'It's to manage, to exclude and it's going to hit those with learning disabilities and those with mental health issues the worst, because it's very much based towards "can you physically do this?"' Lisa (id36), who thinks that due to recent reforms 'the whole system is failing' people with disabilities, also thinks that people with learning disabilities have been badly affected: 'There have been lots of welfare benefit reforms that all have had a particular negative implication for, I think, some of the most vulnerable people in our society who are people with learning disabilities.' Lisa highlights 'the reduction in access to work and supported employment' and claims that 'all of those things have had a real huge impact on young people and adults with impairments and their family carers.' Ellie (id6) makes a similar point in relation to her son's autism, which she describes as 'a non-visual disability.' She says: 'my son can be in a room with 20 other kids and you wouldn't know which one was autistic until something happened.' She contrasts his situation with that for people with other kinds of health conditions: 'if you're in a wheelchair, if you've got Down's Syndrome, if you've got a guide dog, people, society will see you coming and they will know.'

Kattia (id12) talks about negative social attitudes towards anyone who claims benefits: 'It's about people that don't contribute to society. And we're seeing it now with the benefits… you know the stupid [television] programme, Benefits Street.' In this context it is perhaps not surprising that participants tended to contrast their position with that of another person who they saw as less deserving and was abusing the system. For example, Kay (id1) talks about her ex-husband's wife in this way: 'She will swear black and white that she can't walk more than a metre and bit and she'll get everything… Of course she can walk.' This perception that abuse of the system is common can reinforce distrust and suspicion, encouraging support for rules that make it harder to access benefits.

The wider socio-political context, linked inextricably by many participants to the 'austerity' agenda, was seen as a driver for recent changes impacting negatively on disabled people. For example, it was a common view that changes to disability benefits reflected wider negative views of disabled people as non-contributors. Karen (id3) makes this point: 'disabled people are just demonised, they're all sitting on their backsides when they really should be out working and when you're on the receiving end of that, it's horrible.' Ideas about the diminished contribution of disabled people, that they are unproductive, are linked by Jane (id17) to what she considers a fairly systematic approach towards reducing access to benefits: 'That's why I still believe that they have an agenda when it comes to the poor and the disabled and they see us as unproductive members of society, so they will do their best to get rid of us.' Lisa (id36) sums up this argument when she says: 'I just think this administration's agenda around disability benefits is, frankly, fairly immoral and not helpful.'

The view that others think disabled people are scroungers was very common. Penny (id11) says: 'People seem to think that you're trying to scrounge all the time.' Jane (id17) said: 'You are being scapegoated for being poor or for being unwell… you're being a burden and a drain on society.' Pauline (id25.1) describes how people tell her in effect to be grateful for the support she has received even though she has worked all her life, saved and paid into a pension. The harmful effects of the scrounger rhetoric also extended to carers. Lisa (id36) says that 'the welfare changes overall have had a huge leap in negative impact on family carers' and attributes this to 'media messages that have been circulated and sustained about the legitimacy of people with disabilities and their carers and their families, that whole scroungers kind of perspective.'

Some participants highlighted more general negative social attitudes towards disabled people. Kattia (id12) thinks that disabled people are more visible today but this doesn't mean they are treated with respect and 'there are a lot more violent crimes towards disabled people.' She says that she has friends with serious disabilities who 'have had some horrible things done to them, said to them' and that this also relates to 'the treatment from the services as a whole, including benefits agencies [they are] just treated like absolute shit.' Joe (id35) agrees that the current environment is 'nasty' and also talks about 'hate crimes' against disabled people.

Discussion

The analysis identified four overarching dimensions capturing the experiences of the participants and characterising the potentially harmful effects of interactions with the benefit system. Firstly, there are negative emotional, physical health, mental health and wellbeing impacts. Recipients of disability benefits have consistently and significantly worse health than the general population (Garthwaite et al., 2017) and they are stressed and often distressed by having to go through

the assessment process especially, if this needs to involve an appeal. The process can be exhausting, lead to feelings of despair and sometimes mental crisis, for some disabled people the processes are degrading. These findings support Barr et al. (2016), who find that reassessments for disability benefit eligibility are associated with harms, including increase in suicides, self-reported mental health problems and the prescription of antidepressants, that require social action not solely individual intervention.

Secondly, while benefit payments are intended to help meet the costs of disability, they may be insufficient to meet people's needs, while delays and stoppages accentuate financial difficulties. Long-term reliance on benefits can also lead to an erosion of resources, and there are direct costs associated with claiming and managing benefits. These include the costs of communicating with officials by telephone which can be prohibitive as acknowledged in the recent policy reversal on free helplines for Universal Credit claimants (Gauke 2017). The United Nations Committee on the Rights of Persons with Disabilities (UN CRPD, 2017, section 46) has also expressed concerns about 'limited provision of accessible information from public services' for disabled people in the UK.

Thirdly, perverse employment effects arise because benefit rules can discourage disabled people and family carers from seeking work. An example of how these perverse effects can play out is seen in the 2017 change that reduced Employment Support Allowance (ESA) from £102.15 to £73.10 for those in the Work Related Activity Group (WRAG). This change potentially reduces the financial incentives for people to undergo the Work Capability Assessment (WCA) for ESA, but incentives to challenge a decision to be placed in the WRAG rather the Support Group (SG) are higher (Waters, 2017: 10). More disabled people may also apply for Personal Independence Allowance (PIP), which can provide an automatic entitlement to ESA disability premiums. In addition, while some new WRAG claimants (on the reduced rate) may move into work, for many this will not be a realistic option. As argued by Shakespeare et al. (2016: 36), 'Society must accept that work is not always appropriate or possible, and that for many disabled people humane and supportive alternatives to work are needed.'

Lastly, wider social consequences of benefit rules and processes that (dis)advantage some more than others can lead to false economies when disabled people are excluded from social participation. Changes of this kind as well as changes to support provision were commonly attributed to the socio-political context of 'austerity.' For example, changes to benefits for disabled people were seen as a cost-cutting exercise as well as reflecting and, possibly reinforcing, negative social attitudes that demonised disabled people as non-contributors, scroungers, undeserving and frauds. As a consequence, disabled people are stigmatised, which can deter them from claiming benefits or seeking other kinds of help or support (Garthwaite 2011, 2014). For context, under a third of the 8.59 million people (aged 16–69) with a disability or health condition that restricts ability to carry out normal day-to-day activities, access sickness/disability related benefits (ONS 2017). The UN CRPD (2017 section 12) has expressed concerns about perceptions in UK society 'that stigmatize persons with disabilities as living a life of less value than that of others.' This stigmatisation of disabled people receiving welfare benefits is not unique to the UK and extends to carers and benefit claimants more widely (Baumberg 2016; Patrick 2014). Furthermore, these concerns are not new (as highlighted in Bolderson 1974), suggesting inherent, long-term difficulties associated with how social security is organised and administered.

These findings indicate that policy interventions can have unintended adverse effects on the health, work, wealth and wellbeing of disabled people and their families. Such effects appear to be embedded in the quasi-clinical administration of disability benefit systems in ways comparable with iatrogenic damages linked to health care interventions, systems and policy (Illich 2003). This research suggests that these iatrogenic effects should be incorporated into social security systems analysis as has been attempted in analyses of social services (McKnight 1989) and educational and criminal justice systems (Barton 2016). Any such effects of the benefit system on disabled people, their families and wider society need to be better understood and given due attention in both the design and implementation of policy. Here we are reiterating Bonnell et al.'s (2015) call for social scientists to use 'dark logic' models to investigate the processes by which potential iatrogenic impacts of policies and interventions occur. This research has responded to this call by highlighting (post-hoc) iatrogenic effects within the disability benefit system. In relation to 'welfare reform,' consultation prior to enactment and implementation provides opportunities to undertake such modelling and uncovering iatrogenic harms of current policies presents a challenge to select committees and governments to do so more effectively in the future.

The findings reflect the views and experiences of a sample of 49 individuals and do not claim to be representative of people with a disability or family carers and cannot therefore be generalised. In particular, the sample may over-represent people who have faced difficulties trying to claim disability benefits; only seven participants said they had faced relatively few difficulties making a claim. However, while this paper has focused on the potentially harmful effects of interactions with the disability benefit system, participants also talked about the presumably intended, positive effects of being able to access social security benefits. These included the ability to simply survive, the means to meet the extra costs of disability and wider enabling effects linked to independence (e.g. in relation to mobility). As discussed in Patrick (2014) people living on benefits often struggle to just 'get-by' and access to disability benefits can make all the difference between managing or not.

The characteristics of participants varied on a number of levels including the range of impairments, different family relationships and roles and representation of people with a disability who were also caring. The variety in roles highlighted how the lived experiences of disabled people and family carers are interrelated and overlapping, and in particular how the adverse effects of social security extend beyond disabled people to other family members. While these effects were

experienced widely some differences between the experiences of those with mental and physical health impairments emerged. For example, participants highlighted that greater visibility of some physical health impairments could make it simpler to access benefits and other supports. Those with greater access to material, personal and social resources were also assumed to be better placed to withstand negative impacts. Future research would benefit from consideration of how the inequality of harm is structured in relation to impairment category and socio-economic status. It would also be helpful to incorporate representation of disabled people who are also providing care and co-representation from within family units. This would address dominant narratives in policy and previous research which tend to treat 'disabled people' and 'carers' (assumed to be non-disabled) separately relying on traditional administrative categories of disability and care (Kröger 2009). However, experiences of impairment, disability and care embody personal and social relations which, if ignored, potentially weaken the effectiveness of policy designed to support disabled people.

Conclusion

The research findings highlight how interactions with quasi-clinical 'social security' can have adverse presumably unintended, iatrogenic effects on disabled people and other family members. The research also highlights how such effects are transmitted through and shaped by the socio-economic and political environment in which people live. Specifically, in this study, the context is one in which disability benefit changes are being initiated as part of a wider political agenda. Such aspects have been downplayed in policy in part because of an emphasis on biological and psychological factors and by implication, claimants' functional health status, neglecting the impact of social and relational influences on their lives. Implicated here is a particular form of the biopsychosocial model (Waddell and Aylward) which leaves the social context largely absent: a more social biopsychosocial model could instead allow us to turn the lens around to consider how social context, including social policy, impacts on interpersonal and individual wellbeing in relation to impairment and disability. This could assist in considering alternatives to the contemporary model of social security administration and the extent to which iatrogenic impacts could be countered, including but not limited to universal basic income (Mays 2016). Our themes, developed through our participants sharing of their experiences, re-socialise this analysis and integrate temporal aspects of people's lives. These research findings also serve to emphasise the importance of engaging directly with current policy issues in welfare reform when considering the health, wellbeing and social participation of disabled people and their families.

Additional File
The additional file for this article can be found as follows:

- **Supplementary.** Online Data Appendix. DOI: https://doi.org/10.16993/sjdr.607.s1

Competing Interests

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