COVID-19 and Co-production in Health and Social Care
Research, Policy, and Practice

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Realities of welfare reform under COVID-19 lockdown
What disabled and older people actually experience

The Secret Welfare Rights Worker

Since the first lockdown I have spent my days as a welfare rights worker on the phone supporting people to claim the benefits they are entitled to, or if their claim has been rejected, helping them to appeal against this.

The increased importance of welfare benefits in a pandemic

Although understandably the COVID-19 pandemic has resulted in a focus on health and public health policy, income maintenance policy is no less important. In the UK for example, numerous policies have been introduced since lockdown to deal with the two big interrelated problems any such pandemic poses – making people ill and damaging the economy. Fear of spreading infection has resulted in more and more people being temporarily unable to work, furloughed, losing their jobs, or being made redundant as well, as self-employed people losing their income and often their businesses. In such cases in the UK, people may claim universal credit. If they become sick, they may claim employer or statutory sick pay, although as we shall see, the small print gets more complicated.

This means that there has predictably been a massive increase in the numbers of people reliant on UK state benefits. Historically when that happens, for example, during the last World War, with the blitz injuring and making people homeless, or in times of depression and massive unemployment, it often leads to improvements in benefits
policies as many more people discover for themselves that living on welfare is far from the easy option that the right-wing media often portray it as.

COVID-19 has happened following just such a moral panic with the harshest of ‘welfare reform’ policies in operation now in the UK for more than a decade. Under successive governments, welfare benefits reform has been pursued with increasing severity, particularly in relation to those of working age, to force more and more people into employment, regardless of whether it’s available or appropriate for them (Shefer et al, 2016). However, the direction of travel during COVID-19 has been in exactly the opposite direction, with many jobs furloughed and lost through the contraction of the economy and sickness from the pandemic.

The reality of benefit reform for those most at risk

So, what is life actually like for those who are reliant on welfare benefits and, particularly important, what is it like for those overlapping groups who are most at risk from COVID-19 – older and disabled people, family carers, and people with compromised health?

In this chapter, I hope to cast some light on this under-exposed topic from my daily experience as a welfare rights worker working directly with these groups, and – in the spirit of co-production – to offer people’s own direct comments and experience who were faced with just such a situation first hand, while safeguarding their anonymity. Perhaps one such comment from a woman I have been working with sums up the nature and scale of the issues involved.

Everything’s so difficult now. I’m stuck at home with the virus. My children can’t come over at present. I’ve no one to turn to. I don’t know what to do. Have I got to claim Universal Credit? Someone told me I’ll have to claim it. I know it’s a terrible thing.

And the answer is yes, unless qualifying for the furlough scheme, you will have to claim Universal Credit in your
situation to receive your income and ensure housing costs are met. First, though, for readers who haven’t been claimants or advocates, perhaps something should be said about how this system actually operates.

COVID-19 has fundamentally changed the way I work and the situation of many of the people I work with. Before I met face-to-face with people needing help, I got to know them a bit and worked out together how best to make their claim. The UK welfare benefits system run by the Department for Work and Pensions (DWP) does not seem to have changed at all since the pandemic. Dealing with them is a difficult, stressful, and often harsh and painful exercise, as it has been ever since governments and politicians in the UK, and increasingly in other countries, started to talk up their unevidenced belief that many disabled and other claimants are actually ‘scroungers’ and work-shy, and would be better off getting a job rather than living on welfare benefits (Garthwaite, 2011). They called this ‘welfare reform’ as if it were trying to make the system better, when all the evidence shows that they just wanted to get disabled people off benefits regardless of whether they needed or were entitled to them – or not. This is why the rates of successful appeal against DWP decisions to deny or cut off people’s benefits are inordinately high and most people represented by a trained advocate like me, tend to win their case.

Negotiating a hostile system

People are expected to fill in forms that may be 15 to 30 or more pages long – not so much forms as booklets. With more and more of these, claimants are expected to fill them in online. Universal Credit, which is one of the most important, must be done online. You can get help from the Citizens Advice Bureau to start your claim, but to do it over the phone, you have to prove exceptional circumstances to the DWP. Yet we know that the demographics of people seeking such welfare support have restricted access to computers and the internet. Since lockdown, I have had to communicate with people – family members and claimants – almost entirely by phone.
Obviously, this creates problems for people with hearing and visual impairments. But the problems go much further. Many people are still using landlines without loudspeakers. While a few use modern technology like Zoom or MS Teams, in my experience, most don’t. You can’t pick up on the same cues as you can face-to-face. They say things like: ‘I was hoping for a home visit. I thought you were coming to see me at home. Can’t I come in to see you, can’t I come to the office?’

I try and support people to fill in the forms together over the phone. But this is easier said than done. People understandably want to tell their story; they don’t think like a form. They don’t know how to put things in order, and they certainly don’t know what order the DWP wants or what it will regard as relevant. So they may want to give you a detailed account, perhaps of something relevant to them that happened 20 years ago – telling their story, which helps you get an idea of what has happened. Thus, ‘So you said you had a serious heart attack five years ago, now if you could tell me what happened next and how the heart attack affected you.’ But it is difficult for people to remember the sequence of events, what happened next, how it affected them. As one older man, now with memory problems, put it: ‘So much has happened, there have been so many changes. I’d have had to keep a diary to remember all the ins and outs. So many things happening, bang, bang, how can they expect you to remember.’

And something else the DWP chooses not to recognise is that filling in their forms is actually beyond many people. I regularly encounter people whose reading and writing skills are not enough for them to be able to complete the forms. It is not a rare or isolated problem for people. When I could visit them, I could write things down for people, as they told me, if this were the case. It’s not so easy to do this remotely. But for some people, even working out with them what the accurate answer to a question is, is too difficult for them to sort out on the phone. Even when you run through it with them, they don’t have the experience, confidence, or skill to ‘take dictation’. If you are frail, you may not be able to write quickly or well.

When applying for health-related benefits people don’t necessarily know what is wrong with them or understand
all the medication that they have been prescribed. Even if they have received written information from their GP or consultant, they may not know where they put it, or may not even have kept it.

We do not live in a society where everyone is equally medically literate. I have encountered at least two people after they have had a stroke, who have stopped taking their statins because they have read in the Daily Express that they are harmful!

Perhaps most damaging is that our social security system seems to be based on the assumption that the people who need its help want to cheat and defraud it (Garthwaite, 2011). Despite the fact that, historically, levels of welfare benefit abuse are very low and it results in far less lost state income than tax avoidance and evasion, it has become the focus of official discourse. This is particularly important in a system based on proving what’s wrong with you and what you can’t do to secure support, rather than resting on the philosophy of independent living developed by the disabled people’s movement, where the purpose of support is to maximise what people can do and prevent things getting worse.

A system based on perverse incentives

In my experience, most older and disabled people making benefit claims want to emphasise what they can do, what’s possible for them on a ‘good day’, rather than report the struggles they have and how bad things can be for them. This honesty of course plays into the DWP welfare reform strategy of restricting access to benefits and raising the bar as high as possible (Barr et al, 2016). As one disabled woman put it:

It’s like they want you to play up what’s wrong with you. I think it is important to be very honest. I am an honest person. I really try to do things. I try to walk to the corner shop. I tried to have a shower on my own. No, I don’t feel safe in the shower.
So it’s especially important to help people work out what is really possible for them, what they can do without a serious struggle, and not to feel that their need for help casts them as dependent and ‘scroungers’ – as people in their position are increasingly stereotyped. As an advocate, it is therefore essential to try and work with people in a co-produced way that doesn’t disadvantage them because they fall into the traps laid by the system, while not making them cast themselves as pathetic and dependent. The only way to do this is to try and work alongside the person in an equal inclusive way something that is more difficult to do with remote working.

Many people are terrified of Universal Credit, the benefit for people still of working age and under state pension age. It’s also the benefit you have to claim for help with your rent if you are under pension age. They have heard how hard it is to get it, how you don’t get paid quickly. ‘It’s a horrible benefit. I know you have to do it online. The whole thing frightens me.’ A common expression I encounter is. ‘I’ve worked all my life,’ as if other people claiming benefits may not have done. People are disempowered by the sense of shame generated by the current welfare benefits policy and the generation of hostile public attitudes. ‘I’ve never had to claim anything before. I’ve worked all my life and never had to claim benefits before I was made redundant.’

The need for radical reform

The people I work with are some of those most badly affected by COVID-19 and at highest risk from it. They are also among those most significantly impacted upon by the restrictions that have been put in place to try to control COVID-19. Most are resigned to the consequences, but this doesn’t make it any less hard to deal with. For example:

It’s been terrible looking after (partner) with dementia. Day centres are closed. He can’t stay with anyone else. He was going to stay with his son every other weekend for the whole weekend. You aren’t allowed to do that now.
My husband was going every Saturday afternoon to his daughter, then I could see my own son and grandchildren, now I can’t because he’s not allowed to go and I can’t leave him. He sits all day watching the same DVD and I have to keep putting it on for him again. But that’s the only thing that keeps him calm.

One older disabled man, crying, said:

I can’t see my daughter. I’m sticking to the rules. I cried with the GP the other day, he offered me counselling but I can’t talk very well with what I’ve got so I don’t want it. And when I talk about things it makes me very sad. I can’t go out much so people come to me, so it’s important they can’t. It’s awful.

It is difficult to know what the long-term consequences of COVID-19 may be. We know that some people are suffering long-term COVID-19 symptoms but we can guess that the UK benefits system with its present repressive preoccupations is unlikely to be sympathetic and is more likely to question them. So far, there’s been no suggestion that essentially flawed benefits like Universal Credit and Personal Independence Payment (PIP) will be radically reviewed. We can only hope that like the poor law before, with many more people exposed to the benefits system’s operation through the pandemic health emergency and its failings, dragged forcibly into the light, the pressure for real welfare reform will grow and become unstoppable.

**What needs to be done**

- The UK welfare benefits system needs to be subjected to radical reform in line with the philosophy of independent living developed by the disabled people’s movement.
- There are currently no provisions for co-production in the UK welfare benefits system. Such a programme
should be urgently funded with the active involvement of people with experience of living on such benefits.

- Requirements for effective participation and user involvement developed in health and social care need to be extended to the welfare benefits system.

References

