# The Commission on Social Security and participatory research during the pandemic: new context, abiding challenges

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In this chapter we examine a project called the Commission on Social Security, led by Experts by Experience (hereafter, 'the Commission'). The aim of the project is to produce a White Paper style document on social security, setting out policy proposals for a better benefits system. The project takes a ground-breaking approach with all the Commissioners being people with lived experience of the social security system i.e. current or recent benefit claimants (referred to as 'Experts by Experience', the term having been decided on by the people with lived experience who became involved in the project).

The innovative nature of the project means practice and process have become a major source of learning and the key question examined in this chapter is whether, and how, the pandemic posed new challenges to the Commission's deeply participatory ways of working. We begin by discussing the background to the Commission project and then presents key findings, outlining policy proposals before then giving detailed consideration to issues around practice and process. Key themes include: a tension between urgency to act versus long-term planning; the realities of inclusion and accessibility; and challenges around capacity building. We then turn to methodological reflections. This includes the observation that while Covid-19 has largely been heralded as creating unprecedented problems requiring new approaches, the Commission project illustrates that in some ways it is rather the case that the pandemic has highlighted or exacerbated challenges that already existed.

The pandemic has also, to some extent, opened up more opportunities around inclusion and accessibility and how adjustments to conventional ways of working can enable more people to be involved or contribute. What is striking is that because accessibility has always been central to the work of the Commission, much of those adjustments were ones the Commission already had in place. In addition, the move away from more conventional ways of working, made necessary by the pandemic, allowed some people to be more involved than they would have been if more traditional ways of working had continued. With the Commission project we see that Covid-19 has thrown challenges of successfully conducting participatory work into sharper relief, but also find that outcomes are highly dependent on the level to which those challenges had been addressed – or not – pre-pandemic. Thus, this chapter complements others in this book concerned with participatory research, in particular, Chapters Three, Eight and Nine.

## Introduction

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[1] In the spirit of co-production and rejection of hierarchy, we have simply listed the authors of this chapter alphabetically

While there is a considerable history to the formation of the Commission project, two motivations are of particular importance here: the need for new and solutions focused approaches to anti-poverty; and people with lived experience having a central role in policy development. These themes have been discussed previously (Orton, 2019) and are exemplified in Beresford's (2017) argument that there is currently a "well-rehearsed conversation" in which researchers who produce ever more evidence about problems that are only too well known seem to think that by telling the government how much damage its policies are doing it will stop imposing them; or if they show the public how bad things are then "something will have to change". Instead, Beresford (Ibid.) contends that what is needed is to "support people in poverty to develop their own ideas and solutions for change instead of asking them how awful things are". There is a rich and growing literature on what in broad terms can be referred to as co-production, but which encompasses a range of approaches to the involvement of people with lived experience in policy development (see for example, Chapter Eight; Beresford, 2021; Beresford et al., 2021a; Bergold and Thomas, 2012; McIntosh and Wright, 2019; Patrick, 2019; Williams et al., 2021).

The Commission project began with the broad aim of Experts by Experience having a central role in developing solutions by producing a White Paper style document on the future of social security policy. In 2018, funding was awarded by Trust for London for such a project to be developed through a partnership between an academic researcher and two Experts by Experience from user-led groups. The funding application envisaged an advisory board made up of Experts by Experience and professionals, and an Experts by Experience led working group. But initial discussions led to immediate questioning of this approach in terms of whether it provided a meaningful way of involving Experts by Experience. The result was a very significant shift in approach.

In short, it was agreed that to make the work truly led by people with lived experience a project inception group should be formed, with members comprising Experts by Experience. This inception group was formed through the networks of the original two Experts by Experience. In accordance with the funding for the project, the inception group had two non-negotiables: the project must produce a White Paper style document on social security, and people with lived experience must be at the centre of decision making. But what model the project should use and how to proceed were for the inception group to decide.

The group decided that a Commission of Inquiry model should be used for the project. It was also decided that all Commissioners would be Experts by Experience, and there would be a secretariat/support team of 'professionals'. In total 16 Experts by Experience became Commissioners via a wide range of claimant/user-led groups and Deaf and Disabled People's Organisations. They brought with them a diverse range of experience of different elements of the social security system, and diversity in terms of age, ethnicity, gender, and other identity dimensions. The secretariat consisted of two academic researchers, one independent researcher, and a representative of the funder.

In the interests of transparency, the authors of this chapter are an Expert by Experience who acted as Co-chair of the Commission and three members of the

secretariat. The ground-breaking nature of the Commission's approach means that the practice and process of the project have become a major source of learning. This chapter is based on the authors' (auto-)ethnographic reflections on the participatory methods used in the Commission project, findings from which will now be discussed.

**Findings: urgency, inclusion and capacity building**

Before considering issues around practice and process, policy proposals made by the project will be briefly outlined. In February 2020, just ahead of the onset of Covid-19, the Commission set out a number of initial policy proposals. These took the form of key headline ideas as a basis for further work, rather than a comprehensive new scheme. However, the pandemic then dramatically changed the socio-economic context, including debates about social security (see Machin, 2021; Morris et al., 2020; Simpson, 2020; Summers et al., 2021). In summer/autumn 2020, the Commission launched a revised set of draft proposals and commenced a major public consultation on them. The draft proposals include: a Guaranteed Decent Income equivalent to the Joseph Rowntree Foundation's Minimum Income Standard; a completely new approach to disability benefits using the social model of disability; Child Benefit to be increased to £50 per child per week; and a range of supporting points around housing costs, childcare and so on. The final set of proposals will be published in late 2021.

Another key project output which should be noted is a set of five concise principles to underpin social security, which Commissioners agreed in 2019 (available at the Commission's website https://www.commissiononsocialsecurity.org/). The five principles are as follows.

1. Make sure everyone has enough money to live - and support extra costs e.g. to do with disability and children.
2. Treat everyone with dignity, respect and trust, and the belief that people should be able to choose for themselves.
3. Be a public service with rights and entitlements.
4. Be clear, simple, user friendly and accessible to all, involving people who have actual experience of the issues, including from all impairment groups, in creating and running the system as a whole.
5. Include access to free advice and support. Make sure people can access support to speak up, be heard or make a complaint.

Their underpinning nature meant the principles remained relevant to the changed circumstances of the pandemic and were not revised when Covid-19 hit. The principles are discussed in detail elsewhere [Authors, forthcoming – awaiting confirmation] so will not be considered further here. Instead, this chapter reflects on issues relating to practice and process, that were highlighted and often exacerbated by the pandemic. These reflections in turn provide lessons for conducting participatory work. We begin with the urgency to act versus long term planning.

***The urgency to act versus long term planning***

The onset of the pandemic demonstrated how unfit for purpose the current social security system is and the need for urgent action (Garnham, 2020). The Government

responded with some immediate measures such as the £20 uplift to Universal Credit; and the suspension of conditionality, sanctions, the minimum income floor, and face-to-face assessments, which all made immediate and substantial effects on people's lives and demonstrated that rapid, reasonably extensive change was possible. This subsequently led to civil society campaigns for the uplift to be extended to legacy benefits, and then to be made permanent (see, for example, Covid Realities, 2021). Some third sector organisations began another campaign for the rate of Child Benefit to be increased and Marcus Rashford's work on free school meals serves as a further example of an initiative pursuing urgent action (Hansard HC Deb, 24 May 2021). These actions all constitute important steps that could achieve positive material outcomes for millions of households.

However, such measures do not represent a transformation of the Government's approach to social security. They were pragmatic changes to cope with the overnight shut down of much of the labour market and are likely to have been reversed by the time this chapter is published.[2] Nevertheless, they do present opportunities for raising awareness of the inadequacy of levels of benefit payments and provide a potential platform for gaining broader support for more fundamental reform.

A tension between the urgency to campaign for immediate improvements versus long-term planning was a dynamic that has run through the Commission project and was evident pre-pandemic. Within the project this was in evidence as the need to act quickly to make improvements to the benefits system alongside the time-consuming nature of the Commission's work in seeking to develop a holistic and transformative set of proposals. Experts by Experience often expressed anger or frustration with current problems with social security benefits. Self-evidently, people were drawing on their own experience of the social security system including wider and often very personal issues such as racial discrimination while navigating the system as a person of colour; challenges of daily living when a disabled person's impairment is not adequately recognised; or stigma faced as a full-time carer. Discussion was not therefore at an abstract or purely technical level, but rooted in people's personal biographies, including experiences of trauma and struggle. Wanting to be heard has also been a recurring theme. The form that the 'professional' endeavour of the Commission to produce policy recommendations took can therefore not be separated from the personal experiences of Commissioners and how this fundamentally shaped their approaches to the task at hand.

In practice what this meant was on occasions one or more Commissioners explicitly took the position that discussions were taking too long, and felt that the Commission should be moving more quickly to pursuing action. At the same time, however, Commissioners emphasised the need to consult widely on proposals and produce a coherent, convincing proposed plan of action. There was sometimes reluctance to force decisions to be made without issues being talked through and discussed in detail among Commissioners, and time allowed for reflection and engagement with wider networks and groups. This undercurrent of tension between recognising that the

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[2] In July 2021 the government did indeed announce the £20 uplift would end; a 'Keep the Lifeline' campaign continued to challenge this decision.

Commission's way of working required time and long-term thinking, with the urgency to act, characterised the group's ongoing work.

The point to make is that while from an academic view, thinking in terms of short-term amelioration and long-term transformation seems a reasonable analytical approach, for the Commission's Experts by Experience the starting point is grounded in the realities of how badly the current system is failing. Change therefore needs to be both urgent *and* transformative, it is not an either/or choice. One Commissioner emphasised this strain in February 2020 when telling the group that they needed to focus on the fact that "this is real people's lives":  the pressure to get things right, but to get things right quickly, was keenly felt. This in part reflects the solutions-focused approach of the Commission project. Working towards proposals for an improved future system has proved positive in framing work as generative. This avoids centering difficulties (unless Commissioners want to), or mining and exploiting traumas within the research process. We would suggest that the Commission project teaches us that while Covid-19 created a moment where the need for urgent, ambitious policy responses became more widely recognised, that need – and the scale and immediacy of the challenge – was one about which the Experts by Experience were already acutely aware and grappling with.

### *The realities of inclusion and accessibility*

Another effect of Covid-19 has been on inclusion and accessibility. Lockdown meant the cessation of face-to-face meetings and events. Online interactions became the norm, and awareness of digital exclusion then grew (e.g. Baker et al., 2020). At an individual level people had to shield; live in small bubbles or complete isolation; home school and adapt to a wide array of new arrangements. Getting by day-to-day became a challenge for many.

These factors also affected the Commission project, in which inclusion and accessibility had been established as key requirements at the very first meeting of the project inception group and continued to be regularly emphasised. Pre-pandemic Commission meetings were held monthly, in-person and with arrangements made to enable accessibility, for example by booking taxis to enable travel, and having British Sign Language interpreters and Personal Assistants available. It was also possible for Commissioners who could not attend a meeting in person to join or contribute in whatever way worked best for them, with people joining meetings by Zoom long before the pandemic made Zoom use widespread. Supported pre-meeting preparation time was another approach that developed, enabling Commissioners who wished to do so to talk through the agenda and consider any points they would like to make in advance of the meeting proper.

A commitment to inclusion and accessibility extends to the Commission's outward facing work. Commissioners have been consistent in wanting to ensure a wide range of voices are included in the Commission's work and that outputs from the project are widely communicated. In 2019, a public Call for Solutions was issued, encouraging people to submit ideas and suggestions to the Commission for how the benefits system can be improved. Reflecting the concern to make the process as accessible as possible and to include groups invariably excluded by the practices of similar

initiatives, a number of steps were taken. For example, the Call for Solutions document was in produced in Easy Read (a method of presenting written information to make it easier to understand for people who have difficulty reading). Commissioners decided all documentation should be Easy Read by default rather than seeing it as an add-on. When the Call for Solutions went live the bespoke website also used Easy Read and included British Sign Language videos with subtitles and audio so there were multiple ways to access the questions being posed. Accessible ways to respond to the Call were offered. Even more than this, a legislative theatre event and poetry day were held, providing means for contributions to the Call for Solutions to be expressed in ways beyond standard written submissions.

Covid-19 meant an end to in-person Commission meetings and events such as the legislative theatre. Individual Commissioners were affected by the factors mentioned above such as shielding and lack of access to online tools for meeting. Wider consultation was also problematic both in terms of practical issues around not being able to hold in-person events but also many groups ceasing activities or having to concentrate on key priorities and emergency responses to the pandemic.

However, the Commission project was able to adapt and continue, largely due to the recurring theme we raise in this chapter, that is, that many issues highlighted by Covid-19 were already evident in some form and required action, including in relation to accessibility and inclusion. While most Commissioners attended pre-pandemic Commission meetings in-person, meetings were in fact conducted using what are now being referred to as hybrid or blended means. As previously mentioned, the Commission was using Zoom in 2019, well before Covid-19, as a way to facilitate the involvement of Commissioners when for health or other reasons they were unable to attend in person. Ensuring accessibility meant that pre-Covid, Commissioners would sometimes have one-to-one sessions or telephone calls, for example to go through documents or talk about particular policy topics. Physical and mental ill health meant several Commissioners took periods out from involvement in the Commission project and flexible ways of working developed to keep people in touch and catch-up when it was possible for them to re-engage. All of this experience meant it was possible to adapt to the circumstances of the pandemic using some Zoom sessions, but primarily tailoring engagement to what worked for each Commissioner and their individual circumstances and access requirements as had previously been done, with Covid-19 providing further impetus to do so.

Working in such ways enabled progress to continue, for example in developing and agreeing the revised draft policy proposals discussed above, and launching the public consultation online where Commissioners made contributions either live or through pre-recorded film and audio. Online events were used for the public consultation and worked well. Furthermore, awareness of digital exclusion meant that some funding was given to a number of grassroots groups to undertake consultation within their own communities in ways appropriate to local circumstances, especially in relation to conditions created by the pandemic. This process of *enabling* rather than *doing* was a result of the need to respond to the impact of Covid-19 and has been an important learning point. But the major challenges posed by the pandemic were successfully met and project activity continued, largely because inclusion and accessibility were already identified and acted upon as key issues within the Commission.

*Challenges around capacity building*

A further effect of Covid-19 in relation to the Commission project has been on capacity building for Commissioners. Commissioners brought with them to the project their experience and a wide variety of expertise. There was no expectation that Commissioners needed to do more than contribute their experience and expertise, but it was implicit that capacity building would be part of the project. This manifested in a number of ways. For example, in relation to responses to the Call for Solutions, a session was run for Commissioners on qualitative approaches to analysing data. Just before the pandemic, training was held on engagement with the media for Commissioners who were interested (see also Chapters Eight and Nine). At an individual level, some Commissioners were supported in speaking at external events and one person undertook personal development to chair meetings.

Covid-19 brought an end to such activity and no formal capacity building has taken place since the onset of the pandemic. On reflection we can see that pre-pandemic, opportunities for capacity building did arise and were seized, but did not happen as part of a formal, intentional programme of work. The key point is that pre-pandemic, capacity building was implicit within the project rather than an explicit aim. The approach tended to be somewhat reactive and ad hoc rather than there being a clear, explicit strategy. The disadvantage of this was that capacity building often slipped to the bottom of agendas as priority focused on successfully ensuring the project met its aim of producing policy proposals.

While Covid-19 did have an impact on capacity building, arguably the greater problem was with issues evident pre-pandemic and to which insufficient attention had been given. If the project had been as developed in terms of capacity building as it was in relation to inclusion and accessibility, the pandemic would have required adaptation, but the tools would have been in place to allow more capacity building to continue to take place.

**Methodological reflections**

Reflecting on the above returns us to a key concept raised at the start of the chapter: co-production. Beresford et al. (2021b) argue that in the light of Covid-19 there is a need to consider the relative strengths and weaknesses of approaches typically taken in modern politics and public policy and to consider alternatives that could better serve us in the future, with co-production key among these alternative approaches. We note, for example, that disabled people with vast experience of social isolation could have made valuable contributions to 'shielding' policies but typically were not invited to contribute to decision-making processes. The same applies to mental health service users/survivors and mental health organisations, who had developed their own strategies to deal with the consequences of isolation long before the onset of the pandemic.

More broadly, Beresford et al. (ibid. p14) contend that those who are already familiar with the concept of co-production and believe in the value of working in this way are facing significant challenges. Due to its collaborative and inclusive aims, co-production

usually relies on bringing people together, but the pandemic has meant being faced with the challenge of 'co-producing at a distance' which, while seen by some as providing opportunities, is seen by other practitioners as a rather contradictory notion.

In terms of the Commission on Social Security project, however, there is a different concluding point to make. It is self-evident that Covid-19 created a new and hugely changed context and has had myriad effects on the Commission project. But in terms of the challenges created for practice and process, it is not so much the case that the pandemic *of itself* created these, but rather highlighted or exacerbated issues that already existed and which the Commission's ways of working were already tackling. Across the key themes we identify in this chapter: a tension between urgency to act versus long-term planning; the realities of inclusion and accessibility; and challenges around capacity building, the key insight is that challenges were clearly evident pre-pandemic. How well they were responded to after the onset of Covid-19 was more to do with how far they had already been addressed rather than simply to do with the new circumstances being faced.

The concluding point to make, therefore, is that while Covid-19 has largely been seen as creating new problems which have demanded new approaches, deeply participatory ways of working – as sought in the Commission on Social Security project – faced challenges pre-pandemic. These challenges may have been thrown into sharper relief by the changed context, but they are not necessarily of themselves new. The pandemic has illustrated the inadequacies of the current social security system, opening up opportunities for campaigning for change. However, the premise of the Commission's work is that the transformative change which is required cannot take place without Experts by Experience being fully involved in the process of policy development. Thus, participatory research and co-production approaches faced challenges pre-pandemic, during the pandemic and will continue to do so post-pandemic. The lessons learnt during the pandemic will help to further develop participatory research methods and approaches to co-production which are so necessary to creating a social security system which truly works for those who experience it. Context of course matters when pursuing participatory ways of working, but the challenges faced by those committed to such approaches are abiding, and something we must remain vigilant of both through and beyond the pandemic.

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