

Peter Beresford on what co-production means in the COVID era

Co-production in healthcare tries to ensure that the voices of people with lived experience are included in decision-making. Piotr Teodorowski (University of Liverpool), Saiqa Ahmed (ARC NWC) and Irum Durrani (ARC NWC) talked to Peter Beresford, Visiting Professor at the University of East Anglia and co-chair of the disabled people's organisation, Shaping Our Lives, about how COVID-19 influenced co-production in healthcare services and research.

PT: *The pandemic radically changed our daily life. Has it been an opportunity or obstacle in developing co-production in healthcare services and research?*

The answer to that question is complex, because it's been both an opportunity and a hazard.

Many of the people that could have been involved in co-production have died, and many have suffered through COVID. It's been made worse because we have a very divided system of support in this country. People are familiar with the NHS, which operates according to universalist principles. But we also have long-term support services provided through local authorities, which operate according to a very different set of principles based on the old poor law system of needs and means testing. These principles are quite excluding.

One of the problems with COVID in terms of public policy was that there was an immediate rush on the part of policymakers to get people out of the NHS to free up beds for people who might be victims of COVID. The consequence was that thousands of people with long-term conditions were pushed out into residential or domiciliary social care. Many of them were already infected with COVID or became infected, and massive mortality rates resulted.

That's to do with the way our system is fragmented. But it's also a statement about the particular vulnerability of those who struggle as older and disabled people, and the failure to recognise their rights.

You're not a special person because you've got a PhD or you did such and such a training, but for who you are and what you know by your life, what you have learned and what you've gone through.

PT: *During COVID, working online became a new normal. Do you feel that the pandemic influences how we conduct a co-production? Will everything remain online?*

The technology is neutral. It's what we do with technology – which tends to depend on who is powerful, who owns it or who controls it.

There's been a lot of concern amongst progressive and supportive university staff about the way that the great rush to do research has perhaps been at the expense of thinking about maintaining a commitment to be inclusive, and to develop research in partnership with service users.

The way the emergency nature of COVID has been presented has been a disincentive [to co-production] in many ways. It's 'a bit of a luxury we can't afford'. It is not a luxury. If you want to have a whole picture to draw any conclusions from, you need to involve all perspectives. I spoke to somebody early on who was a victim of COVID, and the first thing that they talked about was their loss of taste. They were a bit concerned because it wasn't mentioned in the statements being made about the symptoms.

Over time, we've realised that COVID is very complex: there are symptoms that some get and others don't. Loss of taste is quite significant. Suppose more attempts were being made earlier on to identify that from talking with people, not just as patients, but also as people who know, value and understand their experience. That would have been helpful, but it hasn't really happened enough. We should be more inclusive about what sources of knowledge we begin to turn to.

There have been many lost opportunities, and that worries me. In my organisation, [Shaping our Lives](#), we would like to see the best things from the pre-COVID-19 world around empowerment and inclusion — and the best things we've learned during COVID from distanced working — being taken on and used to help people become more equal partners in their lives, services, and policy development. I fear that this may not happen.

SA: *Seldom-heard and vulnerable communities are most affected by the pandemic. You suggested that these communities are also mostly ignored in public and patient involvement. Could you expand on this?*

We carried out a [national project](#) ten years ago in association with various local disabled people and service user organisations, because we felt that some groups face even more barriers than service users generally. It was obvious concerning ethnicity, for example.

But we wanted to go a bit beyond what was obvious. We worked in association with local organisations. We wanted them to work out which groups they felt they might not be including or be leaving out and make efforts to be more inclusive. What we got from the project was both practical guidance and also research data, and it was much worse than we would have expected. Five groups were penalised. As well as those marginalised through their gender, sexuality, age, disability, and ethnicity, where people lived was very important: those in residential services, refugees, asylum seekers, homeless, or not having citizen status would tend to be left out. If they communicated differently, they were penalised, for example if English was not their first language or if they communicated non-verbally or by signing.

Another was where people would assume either that the person's impairments were so serious or so extreme that they couldn't communicate and be part of a conversation, or that they wouldn't want to be involved.



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If you have a society that seeks to be democratic, which recognises that it's falling short concerning some groups or issues, you put in place additional arrangements to compensate for your failings. Then if they don't work, that's doubly discriminatory. We were finding that the kinds of barriers that operate conventionally in formal politics and policy development were exactly the same barriers that were constraining efforts to change the limitations of policymaking.

Years back, I remember having a conversation with a colleague of mine, a disabled woman who ran an organisation and raised really sensible practical questions. She said, 'Well, there's only ever so much money — we live in the real world. What if you have somebody who you want to come to a meeting, but they can only lie down? And if they come, it will cost such a lot of money, but you might be able to have more people for that same amount. What do you do?' It's a genuine problem, and I remember we did a whole series of conferences for people who were dying. We planned those incredibly carefully, as people might be in pain or distress. We had medical staff present, special chairs and beds. None of these events was long, and it worked, but it was costing loads of money. We have to take on such costs.

The next group is people seen as potentially disruptive. That would sometimes be applied to people who were seen as neurodiverse, autistic or with dementia. I reject that they would be disruptive. You can do so much to make things accessible for everybody without it being necessarily difficult for somebody else.

The final group was people were those who didn't necessarily say what the organisers wanted to hear. It wasn't that they weren't empowered. Perhaps it could be seen that they were a bit too empowered, and they would say things that authorities would get angry with or wouldn't want to do or hear. They were too assertive. If you get a reputation for being someone who can make your case well and argue and keep going and be confident and not be browbeaten, you will get fewer invitations to be involved.

People are frightened by mental distress, and we are told to think of it like any other physical illness

SA: *Who should own the product of co-production?*

Service users should be allowed to be equal owners amongst other people. One of the things I must say about co-production, and it's a point I've seen made by Sarah Carr [an academic and a mental health service user based at Birmingham University], is that every co-production process needs to get you up to speed to be a co-producer. If you say to somebody, we really want to involve you, that's great. But if people don't feel confident or don't have certain skills, they won't really get involved, they will just make up the numbers or they'll get intimidated and eventually go away. We all have to gain skills to do things like this, and we need to recognise that and support people. You should have a right to be able to engage with the process of making change.

ID: *We have seen the growth of mental health and well-being issues exacerbated by isolation and uncertainty during the pandemic. How can co-production assist us with this challenge?*

That's a massive question, and I answer it not only as an academic interested in policy but as someone with my own long-term experience of using mental health services.

It's something I've had to give a lot of thought. When things went wrong for me, I did none of the things that I would ordinarily do. I didn't try to make sense of it through reading and so on. These are subjects that people don't necessarily want to talk about. People are frightened by mental distress, and we are told to think of it like any other physical illness. I think that's really unhelpful advice because it's not just like any physical illness.

If you use mental health services as a child and you are unlucky, you will then be identified as a mental health service user for future times, which is not something you want to do. If you want to be a nurse or a social worker, and then you have difficult experiences, there is a disincentive to get involved with our mental health service for children because then you will be labelled. That might mean you cannot do the job you want to do although, in fact, your lived experience might be terrifically helpful in giving you understanding.

Even someone with severe mental health difficulties, if they get the kind of ongoing support they need, has a really good chance of leading a good and productive life. I know so many people for whom that's true. I also know many people who have taken their own lives. They have been put in a situation where there seems to be no way forward for them. We need to rethink the way we understand what I would call madness and distress, rather than mental health. I think these are problems that have always confronted human beings, which different societies are still not very good at addressing in ways that work. And when you talk to people as mental health service users who have had chances, as I have, to think about this and talk about it with others in similar situations, it's a better picture.

What people most often say is that we need to move away from narrowly medicalised models of distress, where you go to the doctor or you see a psychiatrist and you get medication, to a model based much more on a social understanding, where there's a recognition that mental health issues are connected with the broader world you live in.

ID: *I think you're right, but nobody is accepting the responsibility.*

I think people and service users accept responsibility. I think some people who work with them/us try really hard in very difficult circumstances because the psychiatric and mental health system is underfunded and in many ways misdirected.

I think mental health service users certainly have a real role to play in co-production, and this is another issue of intersectionality. You're not one thing and nothing else, you might be a disabled person, but also because of the oppressions you've faced, you might have been abused as a child, either institutionally or by a member of your family, and that might have had massive consequences for your mental health. Although it's got a lot easier to talk about, it can still be difficult to get ongoing support. I was fortunate that I had support from a really helpful NHS psychologist in times that were not as tight on money as they are now. Obviously I value the contribution of my family, but I think that my psychologist was incredibly important for me to be able to function as a human being, I don't think many people now will get the benefit of someone like her, who was so skilled, for so long. I feel my support was a process of co-production where we listened to and learned from each other. I wouldn't have used the word then, I didn't know the word. We were trying to sort it out together, and I think that's the best kind of helping relationship, and the best way we can do anything.

It has to be equal in how it works. You're not a special person because you've got a PhD or you did such and such a training, but for who you are and what you know by your life, what you have learned and what you've gone through.

We need to have a society where we are allowed to have a better appreciation of social issues. When the personal and the social come together, that's what co-production is also about – recognising that the individual, the person's job, the public policy should come together and that we need to move on from the old, paternalistic world, where some people know better and lived experience isn't given equal value.

Peter Beresford is co-editor of two books ([part one](#) & [part two](#)) with contributions from the UK and beyond exploring COVID and co-production. They are free to download [here](#).

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