Reflections on Making Co-production Work: The Reality of Co-production from an Insider Perspective

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Introduction

This article explores the key areas by which an academic book was co-produced with people from diverse backgrounds and lived experiences (Sealey *et al.,* 2022). Co-production is often now presented as a common-sense shift to delivering public services (Paget, 2014; Durose *et al.*, 2017), with a distinct trend towards co-production in the UK in recent decades (Pieroudis *et al.*, 2019). The book referred to was explicitly written with co-production at its heart, with twenty people involved in its writing: three editors and seventeen co-authors. Of that group sixteen identified as white and four from minority ethnic backgrounds, and ages ranged from 25 to 80+, twelve identified as female and eight as male. This is a collaborative approach to understanding the lived experiences of service users and carers, providing a unique opportunity to consider the reality of co-production from an insider perspective.

In this article, three contributors to the book, two with lived experience, have reflected on the writing process to identify key themes pertinent to making co-production work. Co-production is often seen as complex because of several barriers that limit its possibilities (Connor and Watts, 2014). However, this article will argue that co-production is possible, by building relationships with co-participants, working in an adaptable and flexible way around structures and facilitating the voices of people with lived experience. The process respected the autonomy of

people with lived experiences and acknowledged working with the limitations of the co-production process. In concluding, the piece will reflect on how the lessons learnt through this process can be applied in the future. The article aims to articulate that co-production, if undertaken effectively, can enhance outcomes for all those involved.

Building relationships as co-participants

An important part of the book writing process was that each service user and carer worked directly with a named editor. The rationale for this was that by working one-to-one, each could build on an existing relationship or develop one where appropriate. It further ensured a clear contact point and source of information for each author. Most co-authors were known to at least one editor before the book's conception, and the need for an effective relationship between editor and writer to support individual needs was recognised.

This was important in enabling editors to understand any concerns amongst the co-authors and work together to minimise any anxieties that arose. This was achieved by working with the individual, providing appropriate support, and negotiating the type of co-production right for them. The editor's level of involvement in the development of the individuals 'voice' varied greatly. Whilst for some co-authors only minor editing across their chapter was suggested, others would meet, discuss, reflect, redraft and resubmit. A third group of co-authors met their editor and shared their experiences, with prompts where appropriate. The editor would transcribe, send to the co-author, and arrange a meeting to discuss content.

> As someone with lived experience, I remained conscious of the vulnerability and self-doubt that oppression can entail and that this may apply to authors. As editors therefore, it was essential to recognise and acknowledge the size of what was asked of them, particularly when a person is exposing themselves to public gaze and undertaking such work for the first time. (Joy)

Authors needed to have autonomy over their voice, whilst feeling secure enough with their allocated editor to genuinely co-produce the work together. For example, authors needed to be able to disagree, ask questions or make comments and suggestions about and throughout the process. The benefits of working with someone known to the author were evident.

> I have considered whether the level of personal information shared would have been different had I not known the co-author beforehand. I'm sure that having known them for several years and having a lasting friendship meant I felt comfortable with the process. (Julia)

However, others derived benefits of working with an editor previously unknown to them. One co-author who worked with an editor new to them before the book's inception was a little surprised at the allocation. However, a relationship with the editor was built which was valued, and they have worked together subsequently.

The key point identified about building relationships is that it takes time, meaning interaction over a period of months rather than a single meeting, more typical in a research process. The impetus to proceed at a fast pace in co-production was mitigated and collaborations took pace gradually 'a little at a time', enabling co-authors to feel comfortable with the process (Hatton, 2017).

Adaptability and flexibility around structures

The development of any academic content requires liaison and effective communication with all chapter authors. However, in a book relating to co-production and working with a broad range of people with lived experiences, systems needed to be especially adapted and flexible. The range of people working on the book required the editor's recognition that authors were starting from different places. For example, in terms of educational attainment, co-authors varied from having a PhD to having no formal qualifications. It was essential that every contributor was able to express themselves in a way which felt right for them without feeling inhibited by an unfamiliarity with academic language.

From an academic perspective, there are inevitable expectations and requirements of publishers concerning level of expression, articulation and the ways in which language was used. As considered, publishers' requirements for using formal terms and accurate grammar required individual negotiation. However, there were some areas which editors needed to establish with the publishers and authors as a principle. Key areas explored here are anonymity and confidentiality alongside individuals' wariness of sharing personal information with others. Editors worked closely with, and between, individual authors and publishers, negotiating for the authentic narrative to remain and for phrases to keep their intrinsic meaning, rather than precise sentence structure.

Some authors preferred to communicate by text or telephone whilst others chose email contact. Those without access to Word (or chose not to use it) had their spoken experiences recorded (with permission), transcribed then posted to them for consideration. Editors also needed to be responsive if individuals' preferences changed. For instance, one co-author initially preferred printed materials sent by post but through working with their editor gained confidence to edit their own work using IT.

> Reflecting on the books collation it felt an enormous task, but it was important to me that it was a positive experience for all co-authors. I was excited about having voices of people with lived experience informing a textbook and being heard and seen by a wider audience. I was also working with two other editors with experience and a pragmatic approach. (Joy)

The nature of publishing means that changes are inevitable and that delays can occur. Unquestionably this was compounded by the pandemic, meaning liaison and clear communication between all parties was vital. This was paramount when working with those who may have anxieties around delays. However, reactions were not uniform.

> Initially I preferred to meet in person with my editor but covid impacted significantly and meeting up wasn't possible. Therefore, jointly agreed deadlines for draft submissions became more flexible and we adapted how we communicated. (Julia)

This approach reflects Hickey *et al.*'s (2018, p. 12) observation around the need for a fluid process with 'opportunity for solutions and innovations to emerge from the relationships developed'. It challenges somewhat the routinely held assumption that those with lived experiences require specific skills sets, to be engaged in co-production.

Facilitating the voices of people with lived experience

The process of co-production can be a daunting undertaking, especially the case when writing for any form of publication. Many authors initially expressed doubt about their capacity to participate. 'I'll try but can I do this?' and 'Who would listen to me?' were comments which permeated in the early stages. A recurring theme within the book was the importance of attitudinal barriers to accessing appropriate and timely services and information. When people had experienced years of negative treatment, it impacted upon expectations of how they might be treated individually.

The editors were clear that each person had important insights to share as co-authors who were encouraged to have full belief in their capacity. Likewise, it was imperative that there was no 'us and them' divide between academic editors and authors with lived experiences.

> Throughout the process I never felt any 'divide'. The fact that co-authors were asked to contribute showed the editors wanted to hear people's voices. A few co-authors, including myself, commented on how attending special schools resulted in low level educational achievement—this wasn't perceived by editors as reason to invalidate my experiences. (Julia)

It was surprising to the editors that Julua felt that low education achievement might be a barrier to inclusion in such work. Firstly, as our vision

for the book was that different voices would be heard and equally valued. Secondly, that as an adult the person has attained professional qualifications and experience including at PHD level.

> I then thought back to my own experiences in studying and working within higher education. Completion of PhD had not allowed me to eradicate the narratives from the past. My impairments are invisible, and the impacts can often be mediated, but I still experience points of frustration and oppression. If these continue to affect me in a position of relative influence, then the impacts on others facing challenges daily remain immense. (Joy)

Only through the editors acknowledging such impacts, could they effectively support individuals to find their own voices. It was clear that building confidence amongst most contributors was essential in revealing an 'authentic' voice for each person, such involvement can be important in challenging power differentials, and autonomy amongst others (Foot et al., 2014). Key to this approach is that it perceives people as experts by experience, capable of making meaningful contributions, rather than passive recipients of sympathy.

In terms of individuals finding a voice, there was a need for consensus and understanding of common terms. Whilst publishers will not accept the use of slang terms or incorrect grammar in submitted texts, this may be the natural expression of authors, which allows their real voice to shine through. Exploring ideas together and including such information as 'key learning' in each chapter allowed for a shared understanding of some of the formal explanations required within academic work whilst making it accessible to everybody. For example, co-author's seldom spoke in formal terms used by professionals, such as Community Psychiatric Nurse, instead typically referring to the nurse'.

Respecting the autonomy of people with lived experiences

Three areas considered here are control over content, anonymity and confidentiality. For many co-authors, talking about complex and emotional issues, which often continued to impact negatively on their lives was a concern that needed to be addressed. Control over what information should and should not be included and the personal elements of an individual's life presented, were therefore the authors' decision.

Through the processes outlined in the work, building effective relationships between authors and editors, and providing personalised support at a level that works for them was inherent. This allowed authors to find the confidence not only just to write, but also to select their own inclusion criteria. On occasions, authors initially included parts of their

narrative then reflected and requested their removal, thus enabling autonomy over the information published.

> Co-production worked well in terms of the editor respecting what I chose to share, with no pressure to explain or elaborate further, simultaneously meeting the book's aims and objectives. Very much 'my story, my experience'. (Julia)

Similarly, negotiations with publishers regarding the use of formal academic language meant that authors were not limited by artificial structures. This allowed the reader to have a stronger sense of the realities of such a situation for people with lived experience. It demonstrates the importance of having a clear and inclusive approach to co-production, flexible to the needs of the individuals concerned and of reinforcing this throughout. Control and individual choice are key in counteracting the long-term effects of limiting attitudes and restrictive processes.

In terms of confidentiality, several authors chose to be anonymous within the work, they decided on their own pseudonyms and how their information and descriptor would be presented. Editors needed to be clear that the identity of each person would not be relayed to anyone else without their permission, including their peers.

> From the outset conversations were had about any wish for anonymity or otherwise, likewise around confidentiality and what I may wish to disclose or not. (Julia)

Some authors were concerned that those around them might be identified and therefore chose anonymity. Where other people might have been recognised, through agreement some details were changed, to minimise risks of negative outcomes.

> I saw authors choosing anonymity for fear of criticism of themselves and their previous actions in difficult situations, these needed to be presented without judgement. (Joy)

It reinforced how internalised oppression can continue over a lifetime and how important co-production can be in ensuring people control of their own narratives. It was essential that authors retained full control and choice over which elements of their lives they included and which information was provided.

This reflects Durose *et al.*'s (2012) argument that research should not reproduce unequal power relations and should be about enabling oppressed communities to challenge the dominance of more powerful interests and perspectives. It is only through respecting the autonomy of people with lived experiences that this can happen.

Recognising the limitations of co-production in the book

To this end, so far, this article has explored the positives of the process in writing the book. However, it is important that the limitations of the process are also acknowledged so that they can be addressed.

Firstly, the structure of the book had been agreed by the editors through submitting a proposal to a publisher. Of the three editors, one had both lived experience and was also an academic, so the book's format was arranged by people in positions of power. Whilst how each author articulated their experience was their personal choice, the essential format of the work was already established.

The decision who to invite to participate was predominantly based on people with lived experiences known to editors who contributed to social work programmes at two universities. This was a pragmatic approach to inclusion, allowing previous knowledge of individuals to consider their willingness to undertake such an activity, but it could also be viewed as selective and lacking clarity. Whilst there was some diversity amongst the co-authors, the size and nature of the work meant that not all experiences were included which needs to be acknowledged.

The limitations outlined could be improved through continuous reflection. Open acknowledgment of any mistakes with clear, regular communication in a manner which suits those concerned, all require consideration. If pragmatic requirements of processes such as publishing or government structures impact on the degree to which co-production can be applied, then this requires full transparency. A 'good enough' methodology takes priority over one that is too structured and does not achieve its aims (Durose *et al.*, 2017).

Thoughts for the future

This article has demonstrated some of the complexities and areas for consideration when working with people with lived experiences in co-production and the issues that may arise.

Only one co-author was included in this article: a person with academic experiences albeit from several years ago. Reasons for this decision were that working with many people simultaneously can be complex, particularly when combined with word count and time limitations. Although, we recognise that this work would have been strengthened by the inclusion of other authors with different voices and perceptions.

However, the outcomes of the process should not be negated, and the increased confidence and pride reported by authors in being recognised, continues.

> The publishers accepted the book proposal, this meant they could see the value of a text which provided a new perspective, one written not ABOUT service users but WITH them and the book coming to fruition being a positive example of co-production working successfully. (Julia)

The fact that individual experiences are being shared widely, demonstrates ongoing impacts and continues to reinforce the importance and validity of the work. Recently informing one author that their work had been read and accessed worldwide led to surprise and delight that their writing was helpful and meaningful to others.

> The narratives of so many people's daily challenges are being understood and explored in ways which would be meaningful to the readers and authors regardless of their backgrounds. (Joy)

It has illustrated some of the ways in which thinking needs to be flexible and individual, and how this might be best achieved. It has demonstrated that the development of opportunities for people with lived experience to build more skills and belief in their capacity, to take 'positions of power' and make decisions at a more fundamental level. That will allow more people to be involved in developing proposals, strategies and future publications. This contrasts with the traditional historical approach of academics imposing their interpretations of other people's experiences.

Many of the lessons learnt through the co-production of the book could be applied in other situations. Arguably the most significant factors to consider when engaging in work in this arena, are to have an agreed and shared understanding of what co-production will look like 'in this context'. Additionally, that those with the authority to make decisions, commit to engage flexibly and responsively with the people impacted by their choices. The capacities and insights of people with lived experience need to be both promoted and recognised as primary methods both of understanding social situations and addressing them.

It is hoped that the book and reflection can help others recognise that such an approach is feasible and practicable. The findings from the lived experiences should highlight that co-production also has the potential to be beneficial for everyone involved.

Biography

Joy Fillingham is a lecturer and leads on lived experience involvement in the Social Work Programmes at the University of Birmingham. She is a White British woman. An accident in 1998 led Joy to become a service user, after a decade in charity management, whilst Dementia of a loved one in the 00s led to many years in a caring role. Negotiating with these experiences whilst undertaking a BA, MA and PhD studies, allowed Joy to

understand and seek to challenge the realities of lived experience from multiple perspectives.

Julia Smith is a White British woman who has lived with an acquired physical impairment and been a wheelchair user for many years. Living with impairment means she has ample experiences of being a service user and living with the impacts of social policies over four decades. Having worked in social work settings as a qualified social worker throughout the 1990s Julia then helped to care for three relatives, who following dementia diagnoses required intensive home support and subsequently nursing home care, which she arranged with little support from statutory agencies. Julia later studied for a PhD researching access to mental health provision for disabled women building on research undertaken as part of a Master's in Disability Studies.

Clive Sealey is a lecturer in social policy and theory at the University of Worcester. He came to live in the UK from an early age from Belize. Prior to working in academia, he has previously worked in a variety of community work settings, which reinforced to him the importance of the lived experience of service users and carers.

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