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Embedding the service user voice to co-produce UK mental health nurse education-a lived experience narrative

Abstract:

Accessible Summary:

What is known on the subject?

- Co-production aims to value service user voices and is increasingly used in healthcare
- Less is known about how co-production in nursing education is experienced by service users

What the paper adds to existing knowledge?

- This paper shares the experience of one service user who teaches student nurses in a UK university
- For the first author, the paper highlights that co-producing nurse education has been valuable and rewarding for both a service user and students

What are the implications for practice?

- Co-production has the potential to benefit student nurses, including challenging their perceptions of "difficult" patients. To achieve this, teaching sessions must be equally produced and delivered. By employing and including service users, universities have the potential to improve experiences for students and service users alike.

Abstract:

This paper aims to describe the lived experience of one service user who uses their experience to teach nursing students about mental illness and self-harm. They have found this fulfilling, and received positive feedback from student nurses. Co-production has the potential to support recovery, and when used in nursing education can support students to challenge stigma and negative perceptions about self-harm.

Keywords:

Co-production; Stigma; Self harm; Nurse education; Recovery.

Introduction:

The power imbalance between mental health service users and those who care for them is not only long documented, but also felt by many current service users. Co-production is defined as “the inclusion of people with lived experience of mental illness, as well as their partners, family and friends in the commissioning, planning and delivery of services” (Rethink Mental Illness, 2022). As such, it could be considered to equalise the power imbalance between staff and service users, with the service user ideally being considered an equal partner in service provision and care.

Despite this, whilst co-production may seek to value service user experiences, the current situation is lacking. For example, some argue that co-production is not true, but instead tokenistic. It is argued that there is a need for services to work with service users and carers, and include their voices so that they feel “safe and in control” in healthcare settings (Hafford-Letchfield et al., 2020). Yet, even considering this research, there are limitations in using academic literature to understand co-production. This is because it is not possible for academics to truly understand or speak for service users: the only people who can do this are service users themselves.

This article focuses on the experiences of one mental health service user who is involved in teaching student nurses about mental health care experiences. Co-production is vital in nursing, because nurses are a key profession involved in patient care. In particular,

the nursing and midwifery professional code states that nurses “encourage and empower people to share in decisions about their treatment and care” (NMC, 2018). However, in the current landscape nurses feel they are “running on empty” (Delgardo et al., 2022). This has implications for their resilience, and relates to the nursing work environment being challenging, with issues including poor staffing (Royal College of Nursing [RCN], 2022). It is particularly concerning since nursing attitudes, particularly towards service users who self-harm, are said to be poor (Akinola & Rayner, 2022). Therefore, organisations should be taking efforts to build the trust of service users at all levels, including universities.

Given the importance of nursing attitudes and values, co-production needs to be considered within the context of the motivation to become a nurse. This is particularly important because mental health nursing students are known to enter the profession having experienced issues such as past loss and trauma (Dixon, 2019). They may also be current/former service users and encounter their former nurses as practice supervisors or assessors (Maile, 2022). Therefore, inclusion of the service user voice demonstrates an acceptance of not only service users who are not nurses, but those who are.

This article focuses on the experiences of one mental health service user throughout her journey, ending with her experiences of co-production within nurse education in a UK university.

An introduction to lived experience:

My name is [blinded for review], and I am a mental health service user. I am a primary school teacher by background, valued for the work I did. Unfortunately, I haven’t taught in a primary school setting for 30 years due to mental illness. Nowadays, I still teach, but in a different way-I teach co-production which many people still don’t understand, working part time for a local University and for Rethink mental illness charity. These two roles have been the making of me. I have also been published in relation to my experience

of being restrained and been a keynote speaker at several conferences, including Positive and Safe.

Co-production in my experience is open to wide interpretation, even within the same organisation. All too often consultation and engagement are confused with co-production. Why is co-production so important? By co-producing we can see improvement and organisational development which places lived experience and carer involvement at the centre of all decisions. Without co-production you are in danger of tokenistic involvement. If those with lived experience and their carers want to see real meaningful change, we need to shout from the rooftops when organisations are merely opportunist in the language they use and their understanding of what true co-production means. In this article the term carer lived experience, includes expert by experience and similar terms.

A cake approach to co-production-effective or tokenistic?

We need to think about cake at this point to gain a better understanding of what I mean! When you hear organisations say they do community engagement and co–production take a few minutes to think about how they are serving up their cake! Consultation can be described as being given the opportunity to choose the cake but there is a catch. The baker or organisation have chosen the questions for you to answer. They are the baker or organisation question's and there is no choice to answer outside of the choices they have given you. They have also limited the questions so there is only the opportunity to respond once. They have consulted with you but that is all. They haven't given you the opportunity to truly choose any ingredient that may go into the making of the cake.

I sit on interview panels for my local mental health provider. It's interesting to see how different members of their workforce approach the setting of questions for the interviews. In my experience all too often staff write the questions beforehand, and you are presented with the questions when you arrive for the interview. I will sometimes be asked and consulted as to whether the questions are acceptable. All too often though there is no discussion or

consultation regarding the questions. The questions are set in stone, with little to no input from myself.

A lack of true inclusion:

I may be sitting on interview panel, but I would argue that this is merely tokenistic involvement. How does this make me feel? Though I'm pleased to be sitting on interview panel, I don't believe that my skills are being used as well as they could be. I would describe myself as quietly confident but in this situation of printed interview questions I find it hard to assert myself and state I have further questions that I would like to add. I reflect whether does the responsibility lay with myself to ask for additional questions. I still don't know the answer and I think in part it would depend on whether you know the staff whom you are interviewing with.

Next comes engagement and this alongside consultation is all too often what organisations carry out, in the mistaken belief that it is co-production. Back to the cake analogy. We are baking a cake and haven't yet decided the flavour or design, you can tell us which you prefer, and we will consider your feedback. There are free text boxes, and you are given more choice. You can respond without being limited to questions asked. However, the organisation or baker may or may not decide to go with your ideas. Ultimately the decision is still with the baker or organisation.

A need to support service users who co-produce:

This is engagement, you have had the opportunity to share your thoughts about the cake flavour and ingredients. This can be further related to attending meetings and there being the opportunity to engage and contribute to the meeting. However, it is daunting attending a meeting amongst professionals. What adjustments are made to ensure you can contribute fully? By having two people with lived experience or carers that can help support one another to feel able to contribute to these meetings more fully may help. In my

experience even those with lived experience who are confident can struggle to engage in this situation.

Back to the cake analogy. We would like to serve up something sweet, we are thinking of baking a cake. We would love you to sit and discuss with the baker or organisation and look at the options we have available and tell us what you think, from your experience, people would like. You may choose something outside of our budget, but you will be part of the discussion deciding what is the best value for the most delicious. It might be cupcakes or a flan and not a cake. We will actively communicate with you throughout the process, and you will have free reign to comment. You have equal decision-making powers. This is co-production, and one of the many reasons it is vital is that: if you serve a cake that contains nuts, and someone has an allergy there could be significant difficulties.

Not being valued financially:

If we think about mental health services, how do they know what is working well, what isn't and what further development is needed to improve the services they provide to their local communities? This is how co-production comes into focus. By involving those with lived experience and carers from the very beginning of whatever needs developing or changing you will gain a much better understanding of need. I have had several inpatient admissions and I have been invited to sit on the inpatient documentation working group. This is a voluntary invitation, which is disappointing.

Is my expertise not worthy of payment I find myself asking? I have been invited from the very beginning of the process. There are four members of staff who sit on the working group and me as the lived experience representative. The numbers are small enough that I feel comfortable to articulate my views and challenge. In his role I have influenced and changed the language that was used in record keeping (it was stigmatising and archaic). I have suggested and asked for amendments to the questions that will be asked at discharge (which are used to monitor he care that service users receive during an acute admission). I

believe this example represents co-production in a positive light. Could the mental health service go further? Yes, being paid would send a message that my expertise was truly valued. Even if I declined to be paid for whatever reason, being asked would be nice!

Assumptions about service users:

The decision not to pay service users for co-production might relate to the fact that the Department for Work and Pensions (DWP) has strict rules and guidelines in relation to this and many people experiencing mental illnesses are genuinely scared of the DWP. Some organisations get around this by offering no payment. However, what does this message say? It makes me feel less worthy compared to paid staff colleagues. All too often organisations assume that people like me are on benefits and therefore no payment for your time is offered.

However, I would challenge this assumption, after all I still have bills to pay like all of us do. I believe that if we are to enable those with lived experience and their carers to escape the benefits trap there needs to be a greater understanding and co-operation between the DWP and employers. This could come in the form of offering part-time work, under 16 hours so you are compliant with DWP rules, and yourmental illness or health is not overtly affected.

A good example of co-production:

Another person at my local mental health provider approaches interviews very differently to their colleagues. Initially they set up a Teams meeting where there is literally a blank piece of paper and those who are sitting on the panel discuss what questions are to be asked. Usually, it 3-4 interviewers and we are all equal. Those interviewing are given the opportunity to discuss and share their ideas and potential questions from the outset. Once drafted we are all involved in the reviewing and agreeing the final draft. This ensures the asking of specific lived experience and carer related questions at panel.

This is for me is a good example of co-production. Why does it matter that those with lived experience and their carers are involved from the outset? Because we bring a unique perspective to the process of interviewing and it's important, we are there from the beginning as we will be able to formulate the questions. We will have our own thoughts on what makes an excellent mental health practitioner. The skills and attributes that we may look for may be different to staff employed by the mental health provider. This again is a voluntary role.

Charity work as an empowering experience:

Recently, I have been working with the Rethink Mental Illness charity at a local level. This work has been an eye-opening experience and has changed my knowledge and experience of what co-production can look like. Part of the remit for the Experts by Experience (EbE) leaders we were tasked with leading and co-producing a day where various stakeholders would attend a workshop to discuss and formulate the beginnings of the local mental health strategy. This was daunting. We began by having several meetings what we wanted to achieve, how could we do this, what questions needed asking? We were fortunate to have a co-production manager who was there in the background for support when needed. Ultimately, though the EbE's led on the development of the workshop. This message empowers service users, who have often been powerless at times.

We decided we wanted to share our experiences of receiving local mental health services. We recognised that reading our own experiences would be difficult so read one another's. You could have heard a pin drop as we each spoke. We had made the decision early on that there were to be no Power Point. We also wanted to share statistics to put into context what we were trying to achieve at the workshop. How to share the statistics? We didn't want to read them out as a list, we wanted people to remember them.

Creating impact through innovative methods:

I had the idea of ribbons tied to chairs, each colour representing a statistic such as the 1 in 4 people who will experience a mental health illness. So, 1 in 4 chairs had a red

ribbon. The statistic for suicide that 3 ribbons and the people stood up from those chairs to represent the 3 people who would take their own life during the workshop was met by an eerie silence across the room. We asked those attending to remove their lanyards. The rationale? We didn't want any professional hierarchy in the room.

I recall a moment where an EbE who facilitated a table at the end of the day saying I was working with this group including one particular man who had high status in the local mental health service: the EbE had no idea! We had achieved what we wanted with the lanyards. The EbE's when preparing for the workshop considered what a positive, influential, and importantly achievable mental health strategy would look like. This embodied co-production through leadershop.

We also facilitated evaluation of our work and decided to give attendees the opportunity to consider what wasn't working well. The aim being that we would be able to identify what needed improving. We then moved onto what would excellent mental health services look like including the voluntary sector and social enterprises. Each question posed was facilitated by the EbE's at round table discussions during the workshop. This was a powerful message about co-production.

Becoming a leader through co-production:

Feedback from the day was excellent, including learning points such as a trigger warning for the statistics. This demonstrates the absolute capability and potential of service users, challenging the tokenistic approach where we are included simply to tick a box on a form. Attendees valued the co-production, the role of the EbE's that they had been instrumental in the formulation and structure of the day and that the day had been "different", i.e., no Power Point. What to do with the vast volumes of information from the day? How best to collate it?

This involved a combined effort of staff members and EbE's drafting and redrafting the information from the day. We wanted to understand how the workshop would impact on

attendees lives in the future, what would they recall in months to come was important to the EbE leaders. Months later attendees still talk about the cake analogy and the CEO of the mental health trust asked for the statistics for the ribbon exercise as he wanted to use it for a leadership meeting.

Challenging own misconceptions to become a teacher again:

Although my former teaching career was left behind, co-production has used my skills and brought my voice to educate others. My experience of co-production has been varied and extensive. It first began with the “Better services for people who self-harm project” which was 2007. One of the themes that came out local to where I live was that staff were struggling to understand self-harm, including the reasons behind this coping strategy and the best way to support individuals who self-harm. My then community psychiatric nurse (CPN) who had undertaken further continuing professional development into the subject of self-harm asked me to develop a teaching package on self-harm. I can honestly say I was horrified, as my confidence was rock bottom and my mental health fragile.

When I said no, I couldn’t possibly do so, my CPN gently pointed out that he believed I had the skills to do so, and that I was a qualified teacher so had the knowledge to develop teacher and training resources. I had questions, such as why would nursing staff want to listen to me and would they be overtly critical of a service user developing and delivering training on self-harm? I could think of endless reasons as to why I couldn’t possibly partake in this co-produced work, such as the staff were adults, whereas I had taught children.

I was acutely aware that I may be challenging some commonly held misconceptions. My CPN gradually chipped away at me, building my confidence until I finally said agreed to develop an initial draft of the teaching. So, began my fore into co-production. I developed the “interesting part” as my CPN called it, and he developed the theoretical part. I never believed that I would teach again and yet 14 years since I had set foot in a classroom, I found myself

co-teaching and co-producing a training package about the complexities of self-harm. I felt listened to and validated by not only the CPN but their colleagues who attended the training.

My current role in Higher Education (HE):

I have worked for several years at a university. This role is synonymous of what co-production can be like. There are numerous reasons I state this. There is a co-production co-ordinator, and this helps. Staff I work alongside have a passion for co-production and enable myself and others to be equal partners. At programme meetings there is a standing agenda item for those with lived experience and carer's which places us on an equal footing.

I have been given the opportunity to co-produce lectures including one specifically on co-production. The preparation for this involved both lecturers (as that what I am as an equivalent partner) writing parts of the module, peer reviewing one another's work. The lecture was co-facilitated with each of us contributing to one another's lecture and discussion points. We covered a range of aspects of co-production including literature research and both our experiences of this subject. I can honestly say it was a fantastic experience.

The need to co-produce nurse education:

As you can see my experiences are mixed. There is still a need to value and include service user voices in health. Where could be a better place to start than in the training of nurses and embedding that value from the start? Co-production and lived experience involvement is vital in nursing education as it brings a distinctive perspective to the learning. It should be central to the learning experience.

By and large, I lecture on self-harm and suicidality for the university. I believe that those with a lived experience of self-harm bring a unique and irreplaceable understanding of self-harm. Taught alongside the theory, as this helps students to see the person behind the self-harm. this enables the student to put the theory into practice. Those with a lived experience of self-harm can help nursing students understand what it feels like to be an individual that all too often is judged and misunderstood. I believe it is important to share the

positive experiences I have had with nurses and other healthcare professionals, so they can see the real difference they can make to people's lives.

I have received compassionate, empathetic care where a member of nursing staff has got down to my level of emotion and "walked that journey" with me, when all I have felt is utter despair. This I believe has made a difference to me and my experience of being supported, in that I have felt validated and listened too. The difference this makes cannot be underestimated. I have also been supported by staff who have had little additional training of self-harm from a lived experience perspective and at times their lack of knowledge and understanding has impacted on the nursing experience I have received.

What service users who teach need:

The lecturers who I work with give me the opportunity to debrief afterwards, and their email box is always open. This results in me feeling supported and safe. One interesting element is that lecturers who have worked with me extensively and know me well ask if I'm happy to deliver the lecturer alone which I am. Lecturers who don't know me as well, stay with me which is understandable. This can change the dynamic of the lecture in my opinion. Students tend to be more open when left alone with me, asking more probing questions about my personal experiences, as well as sharing their own personal experiences.

A final reflection on recovery:

The acronym CHIME stands for Connectedness, Hope, Identity, Meaning and Empowerment, and I apply it here to my work and recovery. Co-production continues to be a positive and rewarding experience for me. It has been instrumental in helping me maintain and stabilise my mental illness and wellbeing after a long period of instability. I achieve connectedness by being valued and respected in my relationships with colleagues, peers, family, and friends. I have hope (and optimism) for the future, a purpose, a reason to get out of bed on a morning. I have hope that I can live alongside a serious mental illness and to so with optimism. I am not unlike other people that I also have dreams and things I aspire to.

Co-production allows my identify to the fore, as opposed to my mental illness, raising my self confidence and self-esteem. Recovery to me is a meaningful life as led by me: a life that is purposeful. It is important that I lead on this as I know myself and my illness best. I empower myself so that I work and support my strengths, so I can be the best person I can. This includes monitoring my mental illness, seeking support when needed and being responsible.

A nursing lecturer perspective:

Co-production recognizes that people with lived experience are "experts", seeking to create partnership between services and patients. At our university, service users are involved from the student interviewing process, contributing to decision making regarding applicants. Service users also teach nursing students across the branches, with nursing students receiving rich lived experience around issues such as self-harm and suicide.

The session described by Sam was designed and delivered between us. We sought to increase student nurses' knowledge of service user experience and how this can be used to coproduce healthcare policy and practice. It was delivered as part of a professional practice module for around 300 second year student nurses. The aim was students' successful acquisition of knowledge, which they could later apply in practice to reduce stigma and discrimination, and promote more compassionate care. This embedded their learning within the context of the Nursing and Midwifery code (NMC, 2018), which states that students must demonstrate appropriate values and attitudes.

To organise the session, we discussed what we would individually contribute before merging these and agreeing the content. In particular, teaching students about service user experiences aimed to challenge students' perceptions of "difficult" patients, which is a term many mental health service users are unfortunately familiar with. Our teaching received positive verbal feedback from students, some of whom stayed behind afterwards to discuss what they had learned and the links they made to practice.

Consistent with our success on this occasion, co-production in nurse education is noted to improve students' knowledge, skills, confidence, and awareness (O'Connor et al, 2021). As Sam identified, co-production in nursing education also has benefits for service users, including a feeling of achievement and personal pride (O'Connor et al., 2021). Yet, there are also limitations. One issue was around supporting students with reasonable adjustments who requested the session be recorded. In this instance, Sam declined this request given that personal issues were being shared, and this decision was shared with the students and supported, to affirm that service user wishes around confidentiality are the priority in nurse education.

As we have both already highlighted, teaching undergraduate nursing students can be enjoyable and empowering. However, service users have also experienced frustration if they sense students are not fully engaged (O'Connor et al., 2021). This is difficult to control as nurse educators. In our teaching, students were prepared about the content of the teaching. Sam is a confident and skilled teacher, but less experienced service users who teach may find the situation overwhelming or triggering, which emphasizes the need for universities to offer debrief type support for service users, given their value to student learning. Ultimately, it has been a privilege to work with Sam, and despite being new to the university I believe we work together well and will enjoy working together for a long time to come, to the benefit of ourselves and the students we teach.

Co-producing nurse education:

Co-produced nurse education requires those with a lived experience and carers to be able to articulate their thoughts. Providing support and reasonable adjustments where necessary if someone has additional needs. This is possible by being creative and open minded. It should not be a barrier. Those from disadvantaged and minority communities should be included in curriculum design from the very start, using the cake approach to ensure engagement and success. It is important to have the relevant people working in co-production. There is little point in someone being involved in the co-production of Crisis

services, or in teaching self-harm and suicide, if they have never used this service or experienced those things.

Overall, excellent co-production takes time and a great deal of effort from all parties. It has the capacity to be the instrument for great change. However, if not done correctly it can leave those with lived experience and their carers feeling jaded and not listened to. Co-production is about being at the start of the process, through to the development of mental health services and is about learning from one another. When done well co-production has the capacity to achieve quality improvement, and where best to start than within nurse education, to grow compassion in the future workforce who will care for service users as students and future registrants.

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References:

Dixon, J. (2019) A psychosocial approach to understanding the capacities to care and think critically in student mental health nurses. PhD thesis, University of Nottingham.

Delgado, C., Evans, A., Roche, M. et al. (2022). Mental health nurses' resilience in the context of emotional labour: An interpretive qualitative study. International journal of mental health nursing, 31(5), 1260–1275. https://doi.org/10.1111/inm.13037

Hafford-Letchfield, T., Carr, AF., Faulkner, A. et al. (2021) Practitioner perspectives on service users experiences of targeted violence and hostility in mental health and adult safeguarding, Disability and Society, 36:7, 1099-1124, https://doi.org/10.1080/09687599.2020.1779033

Maile, C. (2022). What do Mental Health Nurses think and feel when the service user becomes their student nurse: Is it really ok not to be ok? Podcast to accompany poster. [Audio recording (mp3)] https://hull-repository.worktribe.com/output/4056938

Nursing and Midwifery Council. (2018). The Code Professional standards of practice and behaviour for nurses, midwives and nursing associates. https://www.nmc.org.uk/globalassets/sitedocuments/nmc-publications/nmc-code.pdf

O'Connor, S., Zhang, M., Trout, K. et al. (2021). Co-production in nursing and midwifery education: A systematic review of the literature. Nurse education today, 102, 104900. https://doi.org/10.1016/j.nedt.2021.104900

Rethink Mental Illness (2022). https://www.rethink.org/news-and-stories/blogs/2022/07/the-importance-of-co-production/#:~:text=Co%2Dproduction%20is%20about%20the,with%20service%20providers%20and%20professionals.

Royal College of Nursing. (2022). 8 in 10 shifts unsafe: RCN survey reveals shocking extent of staffing crisis. https://www.rcn.org.uk/news-and-events/news/uk-rcn-survey-reveals-shocking-impact-of-nurse-staffing-crisis-on-patient-safety-060622