



Conference Report:

Middlesex University Centre for Co-production in Mental Health Inaugural International Seminar 18th July 2016

'Insider, Outsider, Impostor?'
**Perspectives of mental health service
user and survivor researchers and
teachers on co-production in academia**

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Introduction

On July 18th 2016 the Centre for Co-Production in Mental Health initiated its launch seminar entitled 'Insider, Outsider, Impostor? Perspectives of mental health service user and survivor researchers and teachers on co-production in academia'. The conference was attended by 47 people from a variety of different backgrounds including service user researchers, service user community group members, health and social service professional staff, and Middlesex academics.

The aim was to bring together mental health service user and survivor teachers and researchers with their non-user colleagues and students to discuss how co-productive approaches can advance and improve practice. It was therefore hoped that the seminar would offer a unique opportunity to learn about mental health co- production in academia from the perspective of leading service user and survivor experts who would discuss co- production and service user and survivor leadership in research, teaching & course development, and mental health service consultancy. The full conference programme is in Appendix 1.

The conference was opened by Professor Anna Kyprianou, Pro Vice-Chancellor and Executive Dean, Middlesex University Business School, School of Health and Education and School of Law. It was closed by Dr Carmel Clancy, Head of Department of Mental Health, Social Work and Integrative Medicine, and Dr Richard Beaumont, Deputy Dean, School of Health and Education.

Plenary presenters were:

- Dr. Sarah Gordon, Research Fellow, Department of Psychological Medicine, University of Otago Wellington, New Zealand.
- Dr Jayasree Kalathil (Survivor Research)
- Dr Dina Poursanidou (Service User Research Enterprise, Institute of Psychiatry, Kings College London)
- Dr David Crepez-Keay (Head of Empowerment and Social Inclusion, Mental Health Foundation).
- Jane Obi-Udeaja, Garry Ryan and Kate Crosby, Physical Intervention Trainers, Middlesex University
- Nuala Kiely and Penny Fraser Service User consultants (HAIL Haringey, User Led Organisation)

The conference was positively evaluated (see Appendix 3). The purpose of this report is to give an overview of the issues covered in the day and also to begin an exploration of the implications of these issues for mental health research and teaching.

The main aims of the seminar were to:

- Explore the terms of reference of the Centre: what is co-production in mental health and why is it important?
- Examine the perspectives of those with lived experience of mental distress and service use who work in or are involved in the academic environment.
- Examine co-production in practice in terms of its research, education and service development aspects.

These issues were further explored in discussion groups which were led and notes taken by service users themselves.

Conference Proceedings

1. Introductory remarks: Sarah Carr and Peter Ryan

Setting the scene: The uneven playing field (Sarah Carr)



I'm not going to tell you what co-production is because I've a feeling that most of you will have a good idea of what it should be already.

I'll use an image which is a bit clichéd, but one that's quite apt when thinking about coproduction in mental health – generally - and in research, education and teaching. It's an uneven playing field.

People with lived experience of mental distress and service use, experts by experience, survivor researchers, service user researchers and mad identified scholars have to work very hard to play on this pitch. We often work in isolation within and with academia, which makes it challenging to form teams to go out and play.

There are power imbalances in terms of the value placed on certain types of knowledge, research methodologies, epistemologies and investment in user research. Often service user and survivor voices are pathologised and our knowledge marginalised. We have particular relationships to research and education, arising from our own critical self-reflection, positioning and political activism. For many reasons, academia isn't always the most accessible place for people managing mental health conditions. For some survivor activists, working in mental health in academia is seen as collusion. We can find ourselves in confused positions – hence the title of this seminar: 'Insider, outsider or impostor?'

Nonetheless, service users and survivors have made considerable progress in our own mental health research and education practice over the past decade or so. Many people here today, including our speakers, have played significant roles in this in various ways.

We're especially delighted to have Dr. Sarah Gordon give the keynote

presentation today, not just because she's travelled 12,000 miles from New Zealand to drop in on us –well not just us...but...(and thank you to the department's director of research, Tim Weaver, for persuading her!).

Sarah has been a pioneer in the work of bringing together service user and survivor researchers on an international scale and supporting international collaborations among service user and survivor researchers in academia for many years.

Inspired by her work, we'd like you to be able to share experiences, make new connections and meet different people who can support you in your efforts to progress mental health service user and survivor research in academia, and to promote co-production, whatever your background.

We hope today can make a small contribution to consolidating our learning and ideas, to furthering networks, collaborations and alliances, which can all act as powerbases from which to work on making the playing field more even – but also to queer the pitch while we're at it.

Service user co-production: A new paradigm (Peter Ryan)

This conference offers the opportunity to establish a new paradigm in terms of developing a new field of knowledge, previously inaccessible in academia. Traditional approaches to engaging and working with service users in an academic context have been implicitly stigmatic in offering a public role within academic institutions, that role being essentially to reveal in detail to students how and in what way that person suffers from mental illness and is experiencing 'patienthood'. It requires a kind of psychological striptease which 'non user academics' would be reluctant to engage in themselves.

In this sense this traditional role for service user teacher/trainers within academe reinforces stereotypes and delineates 'us and them' distinctions, which fail to recognize that mental health issues are common across the board. Many academics may themselves have serious (but non-disclosed) mental health issues for which they themselves may need and indeed be receiving treatment. The traditional role therefore reinforces false distinctions between those 'with' and 'without' symptoms and mitigates against the kind of transparency which recognizes that all individuals are vulnerable to mental health issues and problems and that more is to be gained by finding ways to a culture of greater openness in which the vulnerabilities, strength and resilience of all can be shared and recognised.

This conference therefore seeks to subject the role of service user researcher or trainers to rigorous and dispassionate analysis and debate. Are service user researcher/trainers 'insiders'? The answer in a way must

be 'no' in that 'insiders' typically deny their own mental health problems and do not usually encourage a culture of openness and honesty with respect to mental health issues and problems. Are they 'outsiders'? The answer to this must equally be 'no' in that by definition they work within academic institutions and are employed by them. Are they then 'imposters'? The answer to this must again be 'no'. On the contrary, they arguably offer a way forward into greater personal and institutional transparency and openness, towards the creation of a culture in which each individual's uniqueness in terms of their own unique blend of vulnerability, strength and resilience can be recognized. The presentations today will each in different ways foster and promote such an approach.

2. Keynote address: Sarah Gordon (University of Otago Wellington, New Zealand)

'Insider, Outsider, AND Impostor': A journey of co-production in academia



Having been employed as a service user academic since 2010, Sarah shared her experience of being an insider, outsider and imposter at various times during her journey of co-production both generally and in relation to a specific project. Based on this experience, she reflected on the barriers to, and enablers of, co-production both now and in the future.

Tēnā koutou katoa

Oha i te whenua o te kapua roa ma

Nō reira, tēnā koutou, tēnā koutou, tēnā koutou katoa

I imagine many of you will struggle with understanding my version of the English without me speaking a completely different language entirely. I recall when I spent some time in the UK as a teenager that one of the English lads I hooked up with would get me to repeat the word 'shut-up' over and over again. I essentially spent the summer with a seemingly very limited vocabulary.

So, in translation – Greetings from the land I hail from, Aotearoa/New Zealand, the land of the long white cloud in the language of the first peoples of our nation, Maori.

Maori tradition dictates that after any such greeting I should sing but I am not going to subject you to that. On occasion I have sung and those who have been subject to that have strongly encouraged me to stick with my day job.

Something else that plays a large role within Maori culture are Whakataukī or proverbs. They are particularly used as a reference point in speeches. In terms of this speech and the subject of co-production it is this whakatauki that I propose to use as our reference point.

Naku te rourou nau te rourou ka ora ai te iwi.

In translation: *With your basket and my basket the people will live*

And, finally, in introduction - the tamoko. The practice of marking the skin to reflect the background and stories of the wearer. This is my tamoko. As you can see it is quite intricate and there is meaning behind each and all of the detail but what I want to highlight for the purposes of today is the gaps or the breaks in the design. This is very unusual for traditional tamoko – generally they are unbroken – however mine was designed specifically this way in order to reflect that my life has often been impacted and interrupted as a result of my experience of mental distress. Now, I have to admit that I am not a great supporter of mad pride, I understand the intentions behind it – to reclaim the language of our experience and everything that comes with that – however personally I find it very difficult to feel pride or in fact any positive emotion in relation to my experience. I struggle particularly with how it has affected my loved ones and with the limits I feel it imposes on my ability to live my life fully. However this tamoko has impacted on that thinking and feeling to some extent – when I see it, which is actually not that often because it is on my back, I see that even with those gaps and breaks in the design this symbolic reflection of my life is still one of beauty and strength and value. And that is key in the context of co-production, that all of us involved come from a starting point where the experience of mental distress is viewed as being a strength and of value to the work that we are doing.

My first professional job ever was what was then known as a consumer advisor to mental health services. It sounds so naïve now but even after applying for the job, a specific requisite of which was that you had personal experience of mental illness, I didn't fully appreciate that EVERYONE would know that I had a mental illness by virtue solely of my

position title. I think that perhaps if I had really thought about it I probably would never have gone there. I struggled at the beginning - most of my colleagues were at best, reluctant, and at worst, actively opposed to me joining them in the planning, delivery, and evaluation of services. As you can no doubt appreciate I wasn't used to being so unpopular however I soon got over that and came to relish the challenge that this position provided.

It was over 10 years later that I was employed in my current role, self-titled service user academic. I had thought that academia would be different - after all, academics are enquiring individuals whose very roles are about developing new knowledge and ways of understanding including by way of challenging accepted views and shining light on established orders. So, on my first day as a service user academic, with no reservations whatsoever, I very excitedly presented my colleagues with this fabulous new resource (ME!) that they now had at their disposal. You can imagine my surprise when the response was at best, reluctant, and at worst, actively opposed. More specifically, they questioned and advised: 'what was so wrong with the research and teaching they had been doing up to that point in time?'; 'they could appreciate that a service user perspective could be of value to some types of research and teaching, but not the types that they were doing?'; 'if this (having service user involvement) is such a great thing, why isn't everyone doing it?' So, an imposter, yes, very much so.

Essentially my role has two key platforms across both teaching and research. That is the co-produced platform and then the service-user led platform. What I have come to appreciate in terms of these two platforms is that both are important and of value but that they require very different approaches and skills - in the case of co-production it is very much about negotiation and compromise; in the case of user-led research it is about fidelity to user priorities, values, and approaches.

What I am going to speak about this morning is the first fully co-produced piece of research that was undertaken by our Department. It is a relatively small piece of work but I feel it serves to highlight many important considerations in terms of co-production. Firstly, what do I mean by fully co-produced?

Essentially it means I was involved as a co-investigator at each and every stage of the research; and what I hope to show you through this presentation is that my involvement in that capacity was significant at each and every one of the stages and led to very different outcomes throughout.

So, to start with the conceptualisation of the project. The project was prompted by a prescription audit where it was found that sleep

medications or hypnotosedatives are frequently prescribed and used for long periods contrary to prescribing guidelines. So, it was proposed that some research be done with psychiatrists to pursue alternatives. I 'suggested' that we extend the brief to include service users; and that, based on my own personal experience of having been prescribed and used hypnotosedatives for well over 20 years, I had a problem with the presumption behind the research aim of pursuing alternatives being that the problem was with practice and not with the guidelines; so I suggested the widening of the scope of the project to be about exploring practice and experience rather than necessarily coming from a starting point of needing to change practice. Some people might question what does my singular experience of hypnotosedatives have to do with anything? It has everything to do with co-production – our job is to influence research based on our own experience and that of other service users; what's more, we shouldn't be made to feel 'less objective' or in anyway less professional because of this - in reality all research comes about from peoples' observations and experiences that they wish to investigate further. And in the case of co-production it comes back to *our experience and observations* being viewed as being a strength and of value in determining what we are going to investigate. So, this is what we did.

Now, to the design of the study. Originally it was planned that we do it all separately – so the academic psychiatrists on our team do the focus groups with psychiatrists and I do the focus groups with service users. I 'suggested' that we design the research process to reflect a shared decision making model of treatment planning as would be the case in practice in terms of the prescription and use of hypnotosedatives. So that is what we did.

In practice, what this meant is that each clinician and each service user attended three focus groups – the first of these they attended as separate groups for the purposes of reflecting on their own perspectives. The data from these groups were analysed and summarised before the second round of groups. During the second round of focus groups, clinicians and service users met separately again, with each group first being asked to consider and validate the themes derived from their first group; and then being presented with the themes from the other group (i.e. the psychiatrists were presented with the themes from service users and vice versa), and being prompted to respond to and reflect on these. Finally, we brought the groups together for one final focus group where they were supported to explore mutually acceptable ways forward. To further support the co-production and shared decision-making approach each of the focus groups were co-facilitated by myself and a psychiatric registrar.

Now to the analysis and write-up. We managed to engage a medical student to assist us with this part of the project which we all welcomed and she was supervised by one of my colleagues. My next involvement

was upon receiving the draft paper for review and minor amendment prior to submission. From my perspective, there was quite a significant problem in terms of an apparent oppositional theme that I had got absolutely no sense of through the focus groups.

It was entitled: *Whose problem is it?* and described as the major difference of opinion between the groups being who should take responsibility for any changes in hypnotosedative prescribing. And so, what transpired was 6 months of to-ing and fro-ing between myself and my colleague with me questioning this theme and her re-asserting it. It was difficult to continue 'holding-out' when the rest of the team had all but signed off. So, an outsider, yes; and necessarily so. You might re-call my statement from the beginning of this presentation that co-production is all about negotiation and compromise. I truly believe that but it is also about being insistent when necessary – having those difficult conversations and continuing to do so if needed. To be good at co-production you need to be able to do all these things – negotiation, compromise and insistence - and to know what and when a situation calls for one or the other. So, after six months the decision was made to go back to the data.

The four key themes that emerged from the co-produced analysis of the data were:

- Both groups find sleep disturbance a challenge;
- both groups experience conflicts in managing this challenge;
- both groups identify and experience barriers to non-medication alternatives.
- As a result both groups expressed a sense of disempowerment with respect to the issue.

However, and perhaps most interestingly that transmuted into a sense of shared empowerment, largely we believe as a result of the process. By the third group, when service users and psychiatrists met together, having first had the opportunity to explore their own and each other's views, there was concordance on a number of key issues. These included the shared position that medications can work well and have a place, particularly in short-term prescribing; that a holistic view to sleep problems in service users should be adopted, with non-medication adjuncts being used in addition to medication; the importance of the doctor-service user relationship when negotiating the use or discontinuation of hypnotosedatives; the importance of the timing of discontinuing hypnotosedatives, planning for it and reviewing their use. At the final focus group both service users and psychiatrists expressed surprise at how similar their views were. So as reported in the published paper the co-produced approach enabled us to move beyond exhortation and accusation in relation to this issue to a place where service users and

psychiatrists acknowledged and shared both the challenges and the solutions.

So, finally to disseminating the results of the research. From my perspective, participants should always be the first priority. I don't know if this is an issue in the UK but in New Zealand, despite ethics conditions and undertakings, reporting back to service users is often tardy or sometimes even overlooked completely. That is not good enough. Another little bug-bear of mine is when co-produced research is not reported or presented in a co-produced manner.... so, on that note, I'd like to introduce one of my colleagues, Dr Giles Newton-Howes [Video – Giles]

So, what is the key learning from our experience of co-production?

Firstly planning of the approach from the outset is key. Any attendance to the actual research prior to establishing the approach by which co-production is to be facilitated will compromise genuine co-production. Such planning must appreciate that good co-production necessarily takes longer – all that to-ing and fro-ing and negotiation and compromise and insistence is a vital part of the process and sufficient time needs to be allowed in order for that to happen. Finally co-production needs to be well-resourced.

Typically positions such as mine are one-offs; and my observation is that we can very quickly become overwhelmed, particularly as the value of our input comes to be appreciated. This is one of the tensions of going from an imposter to an insider. With greater resource comes the need for greater capacity. Increasing service user academic capacity is absolutely crucial if we want to realise the potential of co-production; so that, going forward,

Naku te rourou nau te rourou ka ora ai te iwi

With your basket and my basket the people will live

3. Dr Jayasree Kalathil (Survivor Research)

Reproducing privilege? Racialised psychiatric subjects in the context of co-production



Dr Kalathil's presentation started with an historical look at the concept of co-production, tracing its connections to other ideas that have been employed in the past to create equal partnership working between practitioners, academics and service users/survivors across mental health service development and knowledge production.

"I was speaking with people who categorised personality disorders as 'The Mad, Bad, and Sad'...[and] speaking on a personal level with people who viewed me as (broken/bad) raised issues of power".

Historically, these approaches have not been successful in addressing the issue of racialisation – a process of categorisation and definition of an 'Other' based usually on alleged biological and psychological differences based on 'race', ethnicity and culture. Partnership working with service users in mental health has not, so far, been effective and meaningful in addressing how psychiatrisation and racialisation work hand-in-hand to produce and perpetuate exclusion, privilege and white centrism.

Taking on from personal and professional experiences of 'being involved' in co-production, Dr Kalathil asked whether co-production is different – conceptually and practically – in being able to address exclusion and decentring privilege.

"The task of addressing diversity falls on the heads of those requiring the representation/facing the prejudice themselves."

4. Dr Dina Poursanidou (Service User Research Enterprise, Institute of Psychiatry, Kings College London)

Critical reflections on paradoxes and unsettling relations in the politics of 'co-production' in University-based mental health research



Dr Poursanidou drew on her experience of working as a Service User Researcher in three English Universities to reflect critically on the myths, realities and complexities of 'co-production' in University-based mental health research. The paper sought to trouble the notion of 'co-production' in mental health research in Higher Education contexts by asking a number of hard questions, such as:

- i) Is genuine co-production (underpinned by equal partnerships between mental health service users and non-service user academic researchers) ever attainable in University-based mental health research, if one takes into account the markedly hierarchical, exclusionary and largely non-democratic and non-egalitarian infrastructures, cultures and relations that characterise Academia - even when mental health service users/survivors are not in the picture?
- ii) It has been argued that 'co-production' in University-based research shares similarities with democratic and emancipatory research (Nind, 2014). If we attempt to democratise mental health research in Higher Education through 'co-production', to what extent are we entering a new space which is neither academic research nor survivor activism or advocacy (Nind, *ibid.*)? To what extent are we entering a liminal, in-between space, a difficult, anxious (Nayak, 2014), unsettled and unsettling, contested space which is full of tensions and contradictions but can also open up creative and subversive possibilities (Spandler, 2008)?

iii) Can 'co-production' in University-based mental health research be perceived as 'a paradoxical space' (Rose, 1993; Spandler, 2009) which has potential simultaneously for both emancipation and appropriation/co-optation (Costa et al., 2012)?

iv) To what extent can we talk about 'unsettling relations' (Bannerji et al., 1991; Church, 1995; Church 2005) between mental health service users and non-service user academic researchers in processes of 'co-production' in mental health research? To what extent does the nature of mental health service user/survivor knowledge (mad knowledge) as 'difficult, troublesome and dangerous knowledge' (Pitt and Britzman, 2003; Cooper and Lousada, 2005) contribute to the 'unsettlement'?

Finally, the paper considered the possibilities for genuine partnerships and reciprocal, respectful relationships of trust between mental health service users/survivors and non-service user academic researchers in the field of mental health research.

Critical reflections on paradoxes and unsettling relations in the politics of 'co-production' in University-based mental health research

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Middlesex University Centre for Co-production in
Mental Health Inaugural International Seminar
London - 18th July 2016



My purpose in this paper

- Draw on my experience of working as a Service User Researcher in 3 English Universities
- Reflect critically **on the myths, realities and complexities** of 'co-production' in University-based mental health research
- **Trouble the notion of 'co-production'** in mental health research in Higher Education contexts by asking **some hard questions**

A definition

- **'Co-production'** – together with **'Public and Patient/Service User Involvement'** → the focus of increased attention within policy, practice, education and research in the field of mental health care in the UK in the last decade
- In mental health research, 'co-production' refers to **active input by mental health service users in the research process and knowledge production** in the context of **equal partnerships with academic researchers** (Boyle and Harris, 2009; Needham and Carr, 2009; Gillard et al., 2012)

Hard Questions (I)

- Is genuine 'co-production' (underpinned by **equal partnerships** between mental health service users and non service user academic researchers) ***ever*** attainable in University-based mental health research?

If one takes into account the markedly hierarchical, exclusionary and largely non-democratic and non-egalitarian infrastructures, cultures and relations that characterise Academia - even when mental health service users/survivors are not in the picture...?

Hard Questions (II)

- Or is genuine 'co-production' **an ideal** to aspire to?
- Can we talk about 'co-production' **in absolute terms, i.e. something is co-produced or not?**
- Or we can only talk about 'co-production' as **a continuum... with degrees of co-production?**

Hard Questions (III)

- ‘Co-production’ in University-based research shares similarities with **democratic, inclusive, participatory, user-involved, emancipatory** research (Nind, 2014a)
- Does attempting to **democratise mental health research in HE (through ‘co-production’) change the nature of research itself? How?**

Nind, M. (2014b) *Democratisation of Research Methods*, Talk at ESRC Research Methods Festival, 8-10 July 2014, Oxford, UK

- **Does such democratisation of research change the identities of the people involved? How?**

Nind, M. (2014b) *Democratisation of Research Methods*, Talk at ESRC Research Methods Festival, 8-10 July 2014, Oxford, UK

Hard Questions (IV)

- When we attempt to democratise mental health research in Higher Education through ‘co-production’, **to what extent are we entering *a new space* which is *neither* academic research *nor* survivor activism or advocacy?**

- **A space that we do not understand yet...?**

Nind, M. (2014b) *Democratisation of Research Methods*, Talk at ESRC Research Methods Festival, 8-10 July 2014, Oxford, UK

Hard Questions (V)

- To what extent are we entering *a liminal, in-between space* - a difficult, anxious (Nayak, 2014), troubled, unsettling, contested space which is full of tensions and contradictions but can also open up creative and subversive possibilities (Spandler, 2008; Rose, 1993)

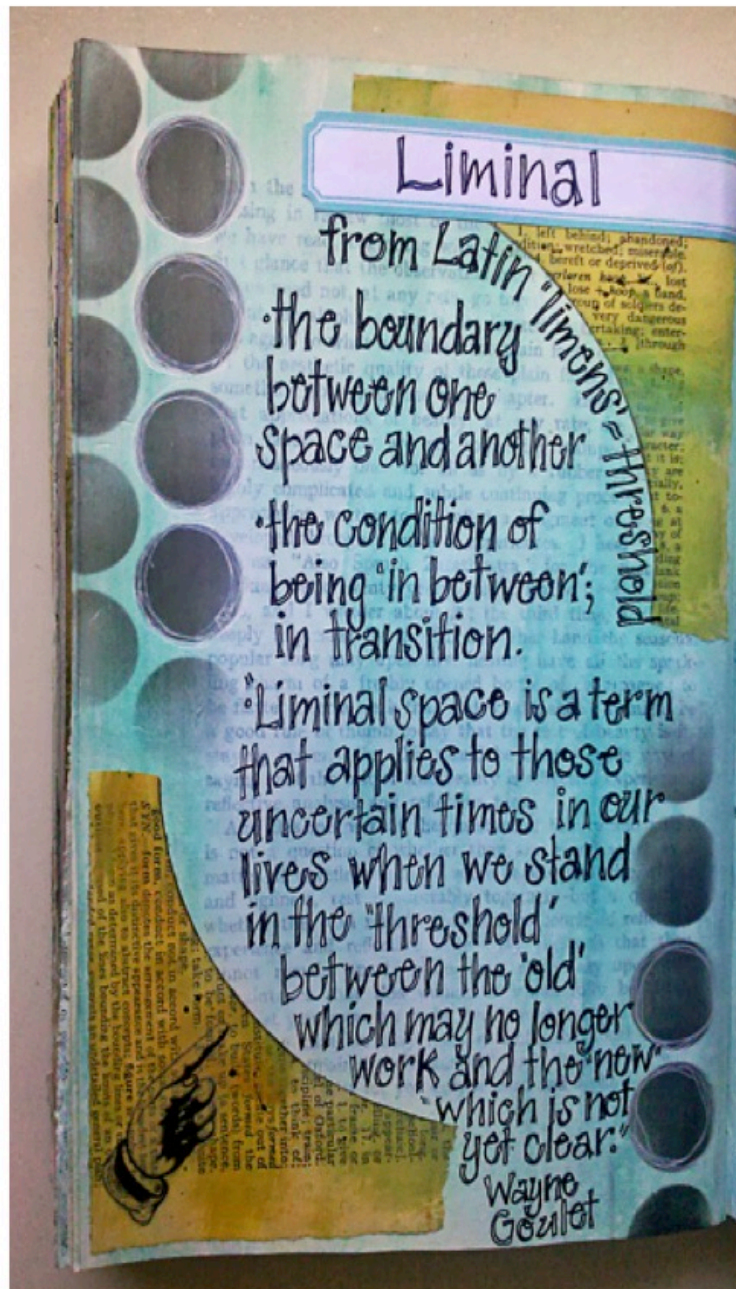
- **'A new space that is loosely bounded and with more pervious boundaries'?**

Nind, M. (2014b) *Democratisation of Research Methods*, Talk at ESRC Research Methods Festival, 8-10 July 2014, Oxford, UK

- **'The lack of clear boundaries involves transgression and threat'** (Jones, 2012)
- **A transgressive space where the rules of Academia are broken? A threatening space? A risky space?**
- **Service user involvement in mental health research as a risky endeavour?**
- In one study (Patterson et al., 2014, p.5) mental health service user participants involved in research acknowledged that **'engaging with or employing service users was commonly perceived as risky in academic environments'**
What exactly is considered 'risky' about engaging with service users?

LIMINAL

(
[http://
mewithmyheadinthecloud
s.blogspot.co.uk](http://mewithmyheadintheclouds.blogspot.co.uk))



Paradoxical space

'Co-production' in University-based mental health research as 'a paradoxical space' (Rose, 1993; Spandler, 2009)?

Potential simultaneously for *both* emancipation and appropriation/co-optation/assimilation (Beresford, 2002; Janes, 2016)?

'[...] Inclusionary practices can at once improve, change and sustain our position as subjugated peoples as we intersect, resist and incorporate into governing ruling relations' (Voronka, 2016)



**Service user involvement
(‘Co-production’) as
appropriation/assimilation/
co-optation**

[...] Many so-called ‘mental health activists’ have become consumed by assimilationist strategies, opting to promote the idea that change can be delivered from within [the mental health system], and advocating peer support and continuing professional education as the new solution to age-old systemic problems: coercion and forced treatment, racism and white supremacy, poverty, homelessness and social isolation ... When did we start seeing the mental health care ‘system’ in the likeness of a group of naïve and idiotic professionals – doctors, nurses, health practitioners, policy makers – who are at the same time well-intentioned and unknowing? And when did we decide that a seat at their table or a moment of their time would make even a bit of difference? What led us to believe that there was power in disclosing our stories, our experiences and our secrets? When did we start deluding ourselves that we mattered that much – or at all, in truth? It would be laughable if it weren’t so pervasive. And dangerous.’

*(Editorial from *Asylum - The magazine for democratic psychiatry*, Volume 20, Number 4, 2013, p.3)*



‘Recovering Our Stories: A Small Act of Resistance’

*‘We all have stories. Many of our stories are deeply personal. Some of our stories are painful, traumatic, hilarious, heroic, bold, banal. Our stories connect us—they reflect who we are and how we relate to one another. **Stories are extremely powerful and have the potential to bring us together, to shed light on the injustice committed against us and they lead us to understand that not one of us is alone in this world. But our stories are also a commodity—they help others sell their products, their programs, their services—and sometimes they mine our stories for the details that serve their interests best—and in doing so present us as less than whole.** - Becky McFarlane, Recovering Our Stories event, June 2011’*

(Costa et al., 2012, p. 86)



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Unsettling relations

- **‘Unsettling relations’** between (non service user) academic researchers and mental health service users in processes of ‘co-production’ in research (*cf.* Bannerji et al., 1991; Church, 1995; Church 2005)
- Would you agree there are ‘unsettling relations’ between (non service user) academic researchers and mental health service users in processes of ‘co-production’ in research?
- What is the ‘unsettlement’ about?

Mad knowledge and unsettling relations: linked?

- **‘Mad knowledge as difficult, troublesome and dangerous knowledge’** (LeFrancois, Menzies and Reaume, 2013; Pitt and Britzman, 2003; Cooper and Lousada, 2005)
- Mad knowledge – mental health service user/survivor knowledge
- Knowledge of traumas; knowledge of mental pain; stemming from engagement with distressing, disturbing, threatening, emotionally disruptive experiences
- Knowledge of ‘unthinkable’, ‘unspeakable’ matters (e.g. madness)
- Mad (difficult, troublesome and dangerous) knowledge and unsettling relations between academic researchers and mental health service users in processes of ‘co-production’ in research – closely linked?

To conclude...

- What are the realistic possibilities for genuine partnerships and reciprocal, respectful relationships of trust between mental health service users/ survivors and non service user academic researchers in the field of mental health research?

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Afternoon presentations

1. Dr. David Crepaz-Keay, Head of Empowerment and Social Inclusion, Mental Health Foundation

Co-production in developing a self-management intervention – training and changing service cultures

David drew his experiences of co-production in a project to design and implement a self-management intervention for people with severe psychiatric diagnoses in Wales to advise on what we can expect of co-production and how we might approach it. People with the experience of severe mental distress took part in developing the model and course materials for the self-management intervention.

“Co-production is the answer to the dreams of the lazy control freak”

There are three very important questions to ask when embarking on any sort of co-productive endeavour in mental health:

1. Who controls the purse strings and who allocates the resources?
2. Who controls what the purpose of the endeavour is?
3. Who decides what success and failure looks like?

Choose partners carefully – go for those who are committed and useful, rather than those who “ought to be there”.

Demonstrate value for money.

Co-production can be controlled by service users, who can then decide which experts to bring in to collaborate with.

“Find people who are really going to provide good value and believe you have something to offer them”

2. Jacqui Lynskey, Service User Associate Lecturer, Middlesex University

Experiences of involvement and co-production in Middlesex University’s mental health teaching

Jacqui’s presentation examined her experience of service user involvement within the Mental Health department in Middlesex University over the last 10 years. She had already been working outside of the university with Barnet Voice for Mental Health as service user run, led and managed group advocacy project for around 10 years and so had built up

a picture of service user involvement in the local trust and other statutory and voluntary organisations, as well as at the University of Hertfordshire.

She reviewed from a service user perspective, how Middlesex has done in terms of working with service user trainers and researchers over the last few years, but also focusing on the future. She examined the challenges that need to be faced and worked on in the future development of service user involvement so that the new world of co-production can become a reality. This will encompass difference in the ways of working together as well as differences in the organisational structure. This will inevitably mean examining whether there is a difference between service user/survivor involvement and co-production, which implies radical realignment of power.

3. Jane Obi-Udejaja, Garry Ryan and Kate Crosby, Physical Intervention Trainers, Middlesex University

Co-production and training in the Prevention and Management of Violence and Aggression

This presentation looked at how co-production developed through a service user involvement initiative in Middlesex University's Prevention and Management of Training Programme, and covered the following points:

- Why user involvement?
- How the service users were recruited
- The contributions of the service users to the team's teaching and dissemination activities
- Feedback on the service users' contribution from course participants and conference delegates
- Is it all tokenistic?
- Future planning

CO-PRODUCTION IN PREVENTION & MANAGEMENT OF VIOLENCE AND AGGRESSION (PMVA) TRAINING

Kate Crosby, Garry Ryan and
Jane Obi-Udeaja J.Obi-Udeaja@mdx.ac.uk

Searching for an effective method



- The limitations of theory and practice taught by professionals to professionals in a 'non-operational environment'.
- The continuous search for ways to improve the training delivery methods in order to achieve service user sensitive restraint practices (DH 2014, Mind and NSUN 2015, NICE 2015).
- Service user involvement can enrich the learning of students and can offer a more stimulating and challenging educational experience that can motivate students to practise more effectively (Tew, Gell & Forster 2004).

Slide 3

Discussions

- **Is there such a thing as ‘Patient-centred’ physical restraint?**



- **What potential rifts might there be between theoretical principles and practice?**

Searching for an effective method



- The limitations of theory and practice taught by professionals to professionals in a 'non-operational environment'.
- The continuous search for ways to improve the training delivery methods in order to achieve service user sensitive restraint practices (DH 2014, Mind and NSUN 2015, NICE 2015).
- Service user involvement can enrich the learning of students and can offer a more stimulating and challenging educational experience that can motivate students to practise more effectively (Tew, Gell & Forster 2004).

Slide 3

Co-Working in PMVA Training



Why involve service users in PMVA training?

- To boost the **authenticity** of our sources and to add realism to what we teach – in order that course participants might be more effectively engaged.
- Service user involvement can **enrich the learning of students** and can offer a more stimulating and challenging educational experience that can motivate students to practise more effectively (Tew, Gell & Forster 2004).

• Course tutors' perspective

- Requesting service users to co-train with us is a step taken in the belief that service users' input would provide the realism needed to support the philosophy of our model of training.
- We experience joy and a real sense of achievement about creating a forum where service users' contributions in our **unique subject area** are intently listened to and valued by practitioners (feedback).

Feedback from course participants

“Service user involvement makes it real. I appreciate this very much”

“Service user involvement is very relevant and thought provoking – a good way to see how our work affects patients.”

“The service user session will help me change practice. It will enable me share knowledge with my team to communicate better with service users. It will help me address their needs and prevent violence. It will enable me deal with violence in a better way”.

“Service user element is the best addition in my view from previous courses – really puts emphasis on considering the client view.”

Feedback from course participants cont.



- “The session was well delivered and highly relevant. Gaining the views of service users and how experiences affect them is really useful for practice”.
- **“Service user perspective was amazing... I could listen to them all day”!**
- “The involvement of service users has given me an understanding of need to de-brief patients after the procedure.”
- **“The part that service users came to talk to us was eye opening and helped us to understand their plight.”**
- “Service user session gave a better understanding and awareness of how it feels to be a service user on a ward and be restrained. It was really very interesting and engaging”.



- Expansion of our service user facilitator base - *to ensure continuity and diversity in restraint scenarios.*
- Exploring other ways of *involvement.*
- *Evaluation* of the impact of service user contribution to the PMVA training.
- Active dissemination and *sharing our experience* of partnership.
- Maintaining *continued support* from the hierarchy.

Conclusion

- Service user involvement boosts the quality of our team's training and continues to attract interest.
- The consistently and unanimously positive feedback from clinicians is an immense source of joy.

In sharing our experience, we hope that training providers co-working with service users would feel reassured and that those yet to do so would be encouraged to try.

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4. Nuala Kiely and Penny Fraser, HAIL Haringey, London

First Steps to Work: Co-producing a service user training programme

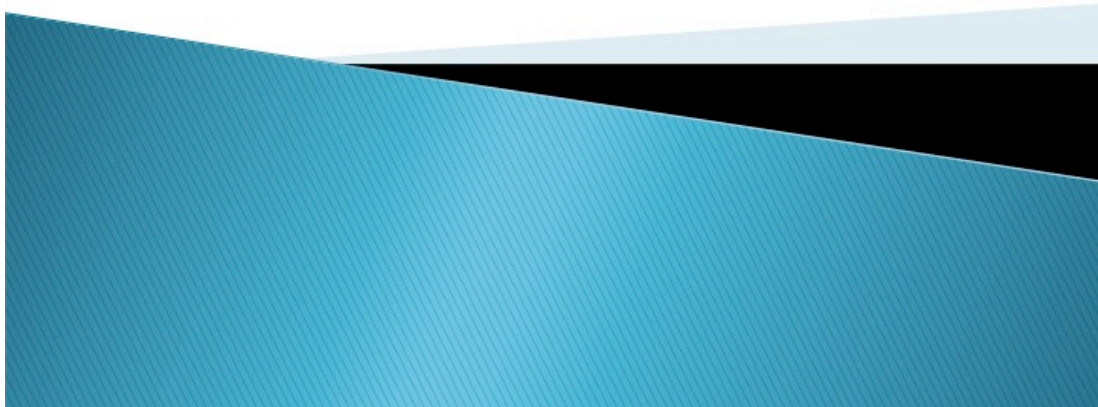
This presentation explored the development of a short course by two peer trainers living and working in Haringey. They worked with Professor Peter Ryan at Middlesex University to co-produce a course directed at mental health service users who wanted to start or return to work. The pilot took place in Autumn 2015 at The Clarendon Recovery College and was funded by Barnet, Enfield and Haringey Mental Health Trust. Over the course of six days, eight students identified their aspirations, skill sets and learning needs. They were equipped with work searching skills, CV development and interview techniques. As the course progressed students increased in confidence and built up relationships with their peers, resulting in a post-course social group.

The evaluation carried out at Middlesex university included wellbeing as well as employment outcomes. Three months after the end of the course three students were in work, another had secured a university place and the rest had started or were awaiting volunteering roles. The next course will begin in September 2016.

First Steps To Work

Co-Production in Haringey

Nuala Kiely
Penny Fraser



Life Long Learning–10 years on.

- ▶ Everyone should have **equal and open access** to high quality learning opportunities
- ▶
- ▶ Education is not just confined to a classroom
- ▶ Education can improve knowledge, skills and competencies
- ▶ LLL facilitates social inclusion of mental health service users.



EMILIA project

Mental Health Service Users in Education

- ▶ Stigma
- ▶ Previous experiences
- ▶ Lower aspirations
- ▶ Lower expectations
- ▶ Lower achievements



Enablement

- ▶ Barnet, Enfield and Haringey Mental Health Trust (BEH-MHT) has made a commitment to enabling service users to move towards training, volunteering and paid employment “DO”
- ▶ Employment support via Individual Placement and Support workers – based within the community mental health teams.
- ▶ First Steps To Work course–Peer Support Worker link



Partnership Working

- ▶ HAIL Mental Health
- ▶ Middlesex University
- ▶ BEH-MHT
- ▶ The Clarendon Recovery College



First Steps a co- produced course delivered by Peer Trainers.

First Steps to Work is a 6 day course which ran for the first time in October 2015

It's overall aim is to provide knowledge and support for students, to identify what paid work , training ,volunteering or “meaningful” activity they would like to do.



Making it work..

All students had to want to work and be receiving secondary care.

Publicity was sent out to Care Coordinators, Recovery Houses, Databases, The Clarendon Recovery College and IPS workers

All those interested received a follow up email and/or phone call. This was repeated 1 week and 48 hours before the course started



Course Content

- ▶ Aspirations
- ▶ Strengths ,confidence building
- ▶ Basic skills
- ▶ CV/personal statements
- ▶ Job searches and applications
- ▶ Interview techniques
- ▶ WRAP



The Learning Experience

- ▶ Loneliness
- ▶ Anxious
- ▶ Lack of confidence
- ▶ Angry
- ▶ Frightened about affects on benefits
- ▶ Numeracy, literacy and IT skills
- ▶ Concerns with passing a DBS check.
- ▶ Immigration difficulties.



Outcomes



- ▶ 8 Students attended each session.

By April 2016– 2 in paid employment

- ▶ 1 started a PSW role
- ▶ 2 in volunteering roles
- ▶ 1 awaiting a volunteering role (unwell)
- ▶ 1 waiting to start university.

Course was positively evaluated.



What we learnt from FSTW

Focus is on students–Listening to experiences and concerns.

- ▶ Everyone’s experience is different including our own..
- ▶ Setting boundaries between “trainer” and “student” is vital. Difficult situations require a debrief.
- ▶ Create a relaxed and safe teaching environment

We don’t have all the answers.



What we learnt from FSTW

Some of our students are very isolated.

- ▶ People with extremely poor literacy and IT skills often don't tell you.
- ▶ Some mental health service users get into trouble with the police when they are very unwell and this affects their future job prospects.
- ▶ **Writing teaching plans takes time!**



First Steps to Peer Support Worker?

- ▶ Lived experience of secondary MH care
 - ▶ Ability to talk about their experiences
 - ▶ At the “right” point in their recovery journey
 - ▶ A commitment to undergo further training
-
- ▶ We Know That Employing PSW's Improves Service Users Experience Of Services.



Moving on.....

- ▶ Follow up group meetings
- ▶ On-going support in applying for jobs and volunteering roles.
- ▶ Enablement champions
- ▶ Repeat course starts in September 2016



Workshop Discussion Groups

Morning Discussion Groups Co-production in mental health research

1. Are there key and unique contributions that service users and survivors can make in mental health research? If so, what do you think they are?
2. Is co-production of special relevance to service user and survivor involvement in mental health research? If so, how and why?
3. Are there any barriers or obstacles to service users and survivors working in mental health research in academic contexts or with academic institutions?

Workshop 1

Unique contributions

Service users can question the language which is sometimes used, the academic jargon. One participant gave an example of the word "pervious" which had been used in one of the morning presentations. This word suggests service users need to pass through barriers.

Are we problematising boundaries?

It is important to highlight problems service users come across in being involved so these can be addressed.

One participant said being a service user is "*a unique contribution in itself.*" They said out a service user can be sectioned or medicated at any time which invokes a different perspective to that of other researchers.

This participant said that being involved as a service user trainer has meant that "*I haven't been asked what my other skills are.*"

Another participant said that "*my survivor experience is an addition to my research skills.*"

Sometimes the complexity of role identity and experiences and perspectives goes unnoticed.

Some therapeutic interventions are more useful than others. Who decides what is offered to individuals and what is researched? Service users can challenge research topics and suggest therapeutic alternatives.

Service users can bring in real world knowledge. They can bring a qualitative aspect to research. They can give a "*voice to the unheard.*"

The relevance of co-production

There was a discussion about what level of service user involvement constitutes co-production.

It is important that service users are involved at the beginning of the process.

Power and responsibility need to be shared to facilitate co-production and to measure its impact.

One participant mentioned the ethical issue of being involved as a research student and entering into the content of the service user experience.

Currently some service user researchers are unpaid. There are financial implications to involving service users in research and paying them appropriately.

Are service users involved in everything? Do they need to be?

Barriers and obstacles

Attitudes. Stigma of "mental illness."

Terminology.

Financing involvement. It is good practice to involve more than one service user researcher to avoid tokenism.

Pathologisation of service user views.

Accessibility.

Academic researchers may be unaware of their own trauma and mental health issues and its impact on the process and practices of research.

Side-lining of service user researchers.

Lack of holistic view by academic researchers, e.g. may not consider social model of disability.

Regulatory framework and its timescales.

Requirements of research funders.

Involving service users can unsettle existing relationships.

Workshop 2

(We amalgamated all three questions into one discussion).

The question assume there is something wrong and lacking
Survivors need to lead - has to be survivors leading

One person recovered by not listening to psychiatric advice.

If therapy reveals you are ill it means you are labeled.

Service users have a contribution to make despite suffering symptoms.

Unique contribution by service users is missing from research.

Need to be involved from the planning stage.

Experience of service users and professionals together is crucial
Not helpful to say psychiatric patients cannot contribute.

Women on wards are vulnerable.

Some mental health activists can come across as blaming drug culture.

Psychiatrists force us to take drugs, it's coercion.

However, respect the help from services as talking therapies help.

"We are experiencing difficulties in this seminar of coproduction, but its good. Energy is good"

Need space and cannot always resolve by talking quickly as it kills the people we love.

In education service users teach students and its good and unique because everyone is different.

Professionals go to service users for advice and help.

There should be help with anger management by service users for service users and professionals. It's a way of putting back into the system when recovered.

Service users play a big role in helping.

Controversial point, people involved in the coproduction within mental health community is hierarchical.

There is a power deficit with the system, but powerful in coproduction.

Subliminal space leads to service users in powerful positions
Get experiences heard? Listen to people's stories, not their diagnosis. i.e. what led you to get there?

All the power lies with medicine so we should listen.

People get distressed because of experiences, so should give space and listen.

Service user augmentation is important in setting agenda.

Need variety, such as more cultural backgrounds as will influence how we make our position.

"If I was going to do some research in geology, I'd need to know the background, so it is the same from working service users, only they know. They have the skills to know best."

Lots of people would like to be involved in research as we've all got unique stories.

We experience stigma, and the experience of being powerless, so we need to be emancipated.

Need to think how we can support each other and take away barriers. Be honest and transparent, what is my role? Is it shared or not the role in research?

It's an idea to make universities more flexible for e.g. in payroll, as can be patronising if don't recognise individual experience.

Barriers to getting into university are huge! Especially for paid work.

Voices have to be heard. Have to be aware of representing unheard voices in a creative way.

Why aren't some people's voices heard, because they are not involved in research?

Need to hear black and minority ethnic groups.

Research always has an agenda. Entering through the back door is how service users get into research.

We would like to get academic qualifications!

Make sure we connect and get together to create a different culture!

Workshop 3

Co-production is something to aspire to. Learn from others who've tried it.

Research and working with academia can be a challenge and an opportunity, but how do you get involved if you've been a service user for some time? How do you get to know opportunities and gain confidence? Some have had negative experiences of education and academia and are reluctant to re-engage. Personal confidence can be affected by the way you're treated in mental health services.

Co-production in research can be more weighted towards well-educated, more articulate service users, with older people with mental health problems and people with lower educational attainment less likely to be included.

Multi-level approach to co-production? Individually tailored, and accommodating fluctuating engagement because of mental health problems. "Person-centred involvement" as a concept for co-production?

Service users may also be wary of working with mental health professionals because of their negative experiences in services. If you've experienced a power imbalance, you anticipate and fear it.

A shared definition of 'co-production' should be established, but if service users aren't defining what it is, they'll get excluded. There's a risk that co-production can become two agencies or disciplines talking to each other about service users. Common language and shared understanding of terms is needed – often people are singing from different songsheets.

Does the idea of a 'third space' create problems and uncertainties? However, this is where change can occur, especially in relationships if service users are not kept in their patient role to retain the power balance.

Do people create 'liminal space' or are they placed there by exclusion and disenfranchisement? Barriers include disability, and invisible mental health disabilities, travel. Simple discriminatory aspects like payment, access and transport can impinge here: "*practical barriers as well as psychological barriers*".

Good practice means fair payment, access to employment and benefits advice. Some service users don't want payment, but this shouldn't be a reason not to offer fair payment. At Recovery Colleges, service user co-trainers are paid equally and this can change perception of value. Fair payment is fundamental: *"why should we be educating educators for free?" "How can co-production be done without payment, it completely changes the dynamic if others are being paid"*.

Can co-production in academia work without payment? Being paid changes the dynamic from being a volunteer to an employee or paid worker. Status is different.

Research teams aren't just the salaried academics. Where do service users fit within the team and organisational structure? How are their roles described and contributions recognised? Are they invited to team events and awaydays?

Often involvement is dependent on the good will of particularly enlightened staff, rather than as standard or as a rule. There should be embedded, consistent ways of working and an organisational structure to promote value and parity. Benefits and employment advice should be dealt with and provided or signposted.

"Institutions can be very hidebound in the way they work which can be disabling".

Institutions to reflect on the way they enable people to take part: information about opportunities; clear communication and structures; engagement and tailored support – then people can make a proper choice about getting involved and this reduces the risk of exclusion.

"The glue along the way that makes the whole work"

"Together out the goal and the steps to get there".

We're still working within a hierarchy. Involvement and co-production depends on leadership commitment from within hierarchy, and commitment from budget holders. A key person to lead who knows the system but who's subversive should be supported as they are so valuable.

Senior leadership is vital – vision and passion. Working with service users, not against them. Leaders should be allies, but it doesn't often feel like leaders are on the side of service users.

Need for peer training in research skills as training is vital for involvement in research. Issues of credibility and recognition, and being named in the outcome, such as being an author on a report of a research project you've been involved in.

Service-user led organisations (like 'Capital') can help with training and facilitation and managing expectations together. People are training in the 'mental health landscape', presentation and meeting skills over a 12 week capacity building course.

Peer modelling is very important – *"I was where you are"*.

Well-funded research projects can be poorly conducted in terms of co-production and service user involvement.

Some non-user academics have said "it doesn't matter about perspective, coding is coding", but this isn't true, everyone will bring a perspective to research analysis, in both qualitative and quantitative projects. No one is truly objective.

Lived experience advisory panels can oversee whole research programmes and department research agendas.

Service users have '2 hats' – a researcher or educator and an individual with mental health problems and support needs. Sometimes these can't be easily compartmentalised.

If you're performing well, that's good but if you're not, then it may be seen as because of your mental health, rather than work. We all have strengths and limitations and things can fluctuate depending on different factors.

You may be penalized if you get involved in research and are in receipt of services, but then if you get unwell it's seen as your fault, as not legitimate. The 'psy' system likes to pigeonhole people, and being active disrupts this.

Are service user researchers threatening to some academics or to staff who feel embattled? Do non-service user researchers and staff get defensive? Are hierarchies and identities disrupted? There is a 'professional trap' which prevents some researchers and staff from taking an honest approach to both their strengths and vulnerabilities.

"The fly in the soup" – crossing status from service user to academic – do you then have to become the person who speaks for all service users? Or can you be a consultant to colleagues who are trying to involve service users?

Is co-production really open to all? There are big power imbalances in mental health. But it's powerful to have the service user train the clinician who treated them.

In a research project or academic initiative, who is 'the team'? What is the place of service users within teams and organisational structures? Are

they core members, or an add-on? Do they exist in a 'third space'? The affects the extent to which service users can contribute to decision making in academia.

It's important to have a service-user co-ordinator to liaise with and support service user researchers and educators.

Afternoon workshop proceedings: Co-production in mental health teaching and education

1. Are there key and unique contributions which service users and survivors can make in mental health education, teaching and curriculum development? If so, what do you think they are?
2. Is co-production of special relevance to service user involvement in mental health education, teaching and curriculum development? If so, how and why?
3. Are there barriers or obstacles to service users working in mental health education, teaching and curriculum development?

Workshop 1

Unique contributions

The individual richness of their experiences.

The power of narratives.

They bring the service user perspective.

They share their expertise and tap into their lived experience.

They can teach alone or with academic.

It mitigates against professionals regarding service users as "other".

Students see the real person and the recovery journey.

Real-time input (academic research may be out of date).

Builds collaborative relationships with students (which may continue when they go into practice).

Professionals can talk openly with service users for whom they are *not* clinically responsible.

From theory to reality to practice to reflection.

They can bring survivor knowledge theory. This is a collective and shared discourse on 'madness' from a perspective of survivor lived experience.

Service users being financially valued.

The relevance of co-production

Is co-production of special relevance to service user involvement in mental health education, teaching and curriculum development? How?

It depends on how co-production is done. For example who finances it, who defines it?

It creates a broad, rich mix

It challenges hierarchies already in place

It embeds the co-production model in clinicians of the future at an early stage

It expands the message outside the mental health knowledge bubble (outside academic research).

Barriers and obstacles

Stigma.

Replicating the power imbalance experienced in services.

When service users don't get paid for involvement this is exploitation.

Lack of parity.

When professionals lack awareness, lack of cultural competency.

Organisational structures and leadership e.g. getting buy-in at a senior level.

Lack of choice, professional development and learning opportunities.

Lack of briefing before involvement and the quality of de-brief afterwards.

Not having enough support from teams or academics.

When service user trainers are reduced to the role of a 'service user' and considered unqualified to speak outside of this.

Students can be anxious about possibility of offending service user trainer.

Lack of funding, resources.

Lack of effective communication.

The culture of partner organisations.

Fear of change.

Need to break down 'them and us' barriers.

Workshop 2

(We amalgamated all three questions into one discussion).

"It is policy"

There is a difference between research and training. Research is the bigger picture. If you don't have the research, you don't have the resources to back up the training. Need a wider approach.

Epistemic knowledge is crucial. If you have a critical framework, then you can use the user voice.

Patient has always been used in psychiatric treatment like a guinea pig!

The story must become the knowledge.

Psychiatric labels are just made up terms.

"I don't want to be involved in other people's committees, but I have to teach in other people's space"

Indigenous studies are a farce because it's a prop in someone else's power agenda.

Language needs to change.

Knowledge transfer goes both ways. It many sound radical but in mental health we want parity of care between mental and physical health.

Nuala and Penny's presentation showed that it is a learning curve for university.

We find ourselves in roles.

Giving and taking in academia is collaboration.

How do you teach service users 'appropriateness'? How does power work?
What am I? What context?

Playing field and terminology has been incorporated into a language, and this language is upsetting.

"University has to work within power structures where the professionals have no say in what happens"

If you invent space together, then you can be in control.

Power structures in universities determine what you can and cannot say.

"We are not free of labels. How we are diagnosed is out of OUR need!"

Recovery College model can break down barriers and power imbalances.

Self-care and boundaries are spoken about and can benefit everyone.

What are the ethics?

Medical models are named as truth, but they're not the be all and end all. Marius Romme gave an enlightened statement that people can recover without the medical model and system.

Recovery colleges do help people but need them to tap into research and evaluation to make them feel they've made a difference.

No resources for creativity.

"What has put me off recovery Colleges is that the agenda is focused on mental health stuff rather than moving on. Immersion in one's illness rather than moving on!"

People with personality disorders can de-stress.

"The brain is plastic and can rejuvenate!"

"It's about discovering and moving on"

"I'm a PERSON using a service, not a service user."

Workshop 3

User-led de-escalation training for police in New Zealand – the police were more responsive to service user trainers than many mental health staff.

Example of 5th and 6th year medical students doing 4 weeks of psychiatry each year, with service user-led recovery component of that education Placements at user-led organisations instead of inpatient units. Recovery component incorporated into assessment, which was turned into a standalone mandatory pass – this changed attitudes as a pass was needed to pass the whole course.

Encourage assessment as a core requisite feature of service user-led and recovery focused programmes. Any added extra won't be attended to by students and if something doesn't matter to their mark, they won't do it.

Students can see things done in services badly, and can find it very difficult or feel guilty. Through user-led training they become sensitive to service user experience, but this may have consequences for their wellbeing: *"Students can feel awful for being part of the system"* but often not empowered to say anything: *"medicine has a hierarchy that encourages bullying"*.

"In New Zealand junior psychiatrists and psychiatric registrars can get progressively acclimatized to oppressive practice, like seclusion. Oppression becomes normalized".

Can we have an uninhibited discussion between practitioners and service users about difficult things, like the use of restraint? Service users can change focus of training from negative attitudes to risk.

Ward practice often doesn't reflect the good practice learned because of fear – how to address and overcome the fear?

Example of Dragon Café in South London where service users and junior or student psychiatrists have open discussions about the effects of psychiatry and psychiatric diagnosis.

Who are the beneficiaries of co-production – focus on service users, not highly paid non-user experts to further their careers.

Students could be placed at or visit user-led organisations and projects. Reduces the 'them and us' positioning – dropping labels, blurring boundaries, breaking down barriers.

Education happens everywhere, not just at the university or in training – it happens in everyday practice.

Diagnostic overshadowing, stigma and discrimination.

Can service users make strategic alliances with practitioner to promote understanding of the social in the bio/psycho/social model? Psychiatrists admit they're not so good at the 'social'. Can we engage in political activism, use accountability systems in CCGs?

There are multiple ways to approach co-production. We should be thinking 'both/and', not just 'either/or'.

Final thoughts and summary of the day

Professor Peter Ryan and Dr Sarah Carr closed the day by asking for delegate reflections and recommendations for how Middlesex University and the Centre for Co-production in Mental Health can support co-production with service users and survivors in mental health research and education.

- Universities can play an important role for capacity building and knowledge exchange with service users, survivors and their organisations. Universities can access and share resources to support co-production and help get ideas out to the "powers that be".
- We need to think about power, ethics and language.
- Explore ideas and methods that co-produce research, like community research methods and other methods outside traditional, clinical research methodology such as sociology, philosophy, history and disability or cultural studies.
- Do we need a guide to co-production?
- Should the Centre link in with other co-production networks, like SCIE's?
- It's unusual to have this type of event at a university, as discussion is usually about services rather than knowledge. A university is a place where we should be able to ask critical or complex questions and can offer space to explore ideas.

- A university has a role in knowledge production and can provide space for taking up co-production practically and intellectually. It doesn't have to be elitist but can provide a 'third space' for collaborative working.
- Remember to "Listen. Learn. Do"
- The Centre will need more publicity and the outcomes of the day should be publicised. There's the chance to link up with other universities doing similar things and to participate in regional partnerships.
- We need to work on a range of research methodologies and new ways of producing and framing knowledge. Can universities make space for critical participatory research?

Appendix One: Conference programme

Morning programme

Morning plenary: Co-production and service user and survivor leadership in research and development in the academic context

9.30-9.40: Welcome and Introduction: Anna Kyprianou, Pro Vice-Chancellor and Executive Dean, Middlesex University Business School, School of Health and Education and School of Law

9.40-9.50: What is co-production? Dr. Sarah Carr and Professor Peter Ryan, Department of Mental Health, Social Work and Integrative Medicine, Middlesex University London

9.50-10.10: Keynote speaker: Dr. Sarah Gordon, Research Fellow, Department of Psychological Medicine, University of Otago Wellington, New Zealand

- 'Insider, Outsider, AND Impostor': A journey of co-production in academia

10.10-10.30: Dr. Jayasree Kalathil, Survivor Research, London

- Reproducing privilege? Racialised psychiatric subjects in the context of co-production

10.30-10.50: Dr. Dina Poursanidou, KIS Research Fellow, Service User Research Enterprise, Institute of Psychiatry London

- Critical reflections on paradoxes and unsettling relations in the politics of 'co-production' in University-based mental health research

10.50-11.10: Panel questions and discussion (Chairs: Professor Peter Ryan and Dr Sarah Carr)

11.10-11.30: Break

Morning workshops

11.30-12.30: Workshops – Co-production and service user and survivor leadership in research and development in the academic context. Participants will be encouraged to reflect on the morning's presentations and their own experiences in facilitated discussion on how to improve and advance co-production in mental health research. There will be a facilitator and note-taker at each table.

12.30-1.30: Lunch

Afternoon programme

Afternoon plenary: Co-production and service user and survivor leadership in education, training and development

1.30-1.50: Dr. David Crepaz-Keay, Head of Empowerment and Social Inclusion, Mental Health Foundation

- Co-production in developing a self-management intervention – training and changing service cultures

1.50-2.10: Jacqui Lynskey: Middlesex University's service user and survivor teachers and researchers

- Experiences of involvement and co-production in Middlesex University's mental health teaching

2.10-2.30: Jane Obi-Udeaja, Garry Ryan and Kate Crosby, Physical Intervention Trainers, Middlesex University

- Co-production and training in the Prevention and Management of Violence and Aggression

2.30-2.50: Nuala Kiely and Penny Fraser, HAIL Haringey, London:

- First Steps to Work: Co-producing a service user training programme

2.50-3.10: Panel questions and discussion

3.10-3.30: Break

Afternoon workshops

3.30-4.30: Workshops (with facilitator and note-taker) - Co-production and service user and survivor leadership in education, training and development. Participants will be encouraged to reflect on the afternoon's presentations and their own experiences in facilitated discussion on how to improve and advance co-production in mental health research. There will be a facilitator and note-taker at each table.

4.30-4.50: Final thoughts and summary of the day: Dr. Sarah Carr and Professor Peter Ryan, speakers and delegates

4.50-5.00: Thanks and close: Dr Richard Beaumont, Deputy Dean, School of Health and Education and Dr Carmel Clancy, Head of Department, Mental Health, Social Work and Integrative Medicine.

Appendix Two: Speaker biographies

Dr. Sarah Gordon, Research Fellow, Department of Psychological Medicine, University of Otago Wellington, New Zealand

Sarah has spent the last eighteen years working and advocating for an improved mental health sector and societal perceptions of mental health from a service user focused perspective. Since 2010 this has involved working as a service user academic for the Department of Psychological Medicine, University of Otago Wellington, New Zealand, undertaking both co-produced and service-user led research and teaching. For the past 5 years Sarah has convened the annual international Service User Academia Symposium.

Dr. Jayasree Kalathil, Survivor Research, London

Dr Jayasree Kalathil is a researcher and survivor activist and runs the virtual collective, Survivor Research. She has a background in critical humanities and cultural studies. For over 18 years, she has worked to link activism and experiential knowledge to academia and knowledge production, mobilising community participation to influence policy and practice.

Her research focuses on issues of racialisation, gender and human rights in mental health, with several publications in these areas, including *Dancing to our own tunes* (2008), *Recovery and resilience* (2011) and the co-authored book *Values and ethics in mental health* (2015). She advises NAZ's BME/LGBT project '1000Women', and is a coordinator of the Inquiry into the 'Schizophrenia' Label. She is currently co-editing a special issue of the journal *Philosophy, Psychiatry & Psychology* on the theme 'mental health user/survivor research and co-production'.

Dr. Dina (Konstandina) Poursanidou, KIS Research Fellow, Service User Research Enterprise, Institute of Psychiatry, Psychology and Neuroscience, King's College London

Dr Poursanidou has a background in psychology and education and have been a University-based social science researcher since 2000. My research has spanned a range of fields, such as mental health, education, child health, youth justice, and social policy/social welfare.

She started using mental health services in 2008, and had her first major mental health crisis in 1991 when I was studying for a Master's degree, and a second very severe and enduring mental health crisis between July 2008 and June 2010 which resulted in a 3-month long detention under a Mental Health Act Section in an acute psychiatric ward, as well as in a 2-year period of unemployment.

Following this crisis, she worked in two Universities in the north of

England as a Service User Researcher. Currently, I am working at the Service User Research Enterprise (SURE) in the Institute of Psychiatry, Psychology and Neuroscience at King's College London. I have a 3-year Post-doctoral Research Fellowship and I am carrying out an ethnographic process evaluation of a violence reduction programme on inpatient psychiatric wards.

Since 2010 she has been a member of the Asylum magazine editorial collective– Asylum, the magazine for democratic psychiatry, provides an open forum for critical reflection and discussion of mental health issues.

Dr. David Crepaz-Keay, Head of Empowerment and Social Inclusion, Mental Health Foundation

David has worked for the Mental Health Foundation for ten years. His goal is to create strong and effective voices for people directly affected by mental ill-health. His department is responsible for developing and delivering service user involvement, carer involvement, self-management and peer support, and mental health awareness training.

With more than 30 years' experience in service user involvement, David has previously occupied a number of prestigious posts including chief executive of Mental Health Media, former board member and vice-chair for the Commission for Patient and Public Involvement in Health, founding member of National Survivor User Network (NSUN), and former chair and treasurer of Survivors Speak Out. In his spare time, David pursues his interest as a qualified cricket umpire.

Jacqui Lynskey, Service User Associate Lecturer, Middlesex University

Jacqui is passionate about service user involvement. Her main aims are to support service users to have their voice heard on all levels and to support them to take control of their lives. She has worked with Barnet Voice for Mental Health, a user run, led and managed group advocacy project, for the last 20 years in which there was a strong connection with Barnet, Enfield and Haringey MH Trust in training, interviewing and research. This also involved working together with the Trust to set service user standards for involvement.

Jacqui's connection with Middlesex University began in 2006, on the newly set up Advisory group; the EMILIA project to see whether involvement in lifelong learning could help service users move onto employment; also in many other research projects and training. She has also been working with UCL for last 5 years on the CORE project as a working group member, on the fidelity process with crisis teams and as a Peer support worker.

Jane Obi-Udeaja, Garry Ryan and Kate Crosby, Physical

Intervention Trainers, Middlesex University

Jane Obi-Udeaja is a physical intervention trainer within the Middlesex University Prevention and Management of Violence and Aggression (PMVA) team. Since 2003 she has continuously researched her subject area in order to improve her team's training service. Jane initiated her team's co-training with mental health service users who have experienced being physically restrained – an innovation intended to motivate practitioners to translate learning into practice. She leads her team in their dissemination activities including: conference presentations and publications. Her qualifications include: MBA, PGCertHE, MSc and MProf. She is currently conducting a research for her Doctorate in Professional studies (DProf).

Garry Ryan entered the mental health system in 2000. An insight into his illness and positive attitude enables him to engage in numerous activities including sports and world travels. A musician by profession, he has produced his own Reggae album. Garry supports and chairs meetings of service users in his Borough. He won an award as the most progressive service user. As a member of the prevention and management of violence and aggression (PMVA) team at Middlesex University, Garry participates actively in the team's conference presentations nationally and internationally and contributes to the team's publications.

Kate Crosby worked as a Mental Health Patients' Advocate in forensic units. She has considerable experience both at personal and professional levels of mental health services. She and her colleague co-authored "Power Tools: a resource pack for those committed to the development of mental health advocacy" (Crosby and Leader 1998). Kate is currently involved in teaching and learning activities at Middlesex University including training hospital staff and nursing students on the Prevention and Management of Aggression and Violence. Kate actively participates in the team's conference presentations

Nuala Kiely and Penny Fraser, HAIL Haringey, London:

Nuala lives and works in Tottenham. She has worked as a mental health service user engagement coordinator at HAIL, (Haringey Association for Independent Living) for the last 4 years. She enjoys teaching including: medical professionals, police, volunteers, service users and carers on various topics around mental health. As a service user herself, part of Nuala's role is to be a voice for service users particularly in the development of new and current mental health services in Haringey. Prior to this post, Nuala worked in health and social care for 12 years in hospitals across London. She is currently a Trustee at Healthwatch Haringey.

Penny currently works as a Mental Health Service User Engagement Coordinator at HAIL Mental Health (Haringey Association for Independent Living). Penny has used mental health services in various parts of London for over 20 years. This experience led to a previous role as a Volunteer Mental Health Advocate at a local charity. Penny has also worked at various levels in Central Government and the Commercial sector. Her areas of interest are wellbeing and mental Health in the workplace and mental health and the BMER (Black, Minority Ethnic and Refugee) communities.

Appendix Three: Event evaluation

Evaluation feedback on 'Insider, Outsider, Impostor?': Perspectives of mental health service user and survivor researchers and teachers on co-production in academia, 18th July, 2016

Number and distribution of responses

9 returned in total:

- 4 service user researchers
- 1 non-service user researcher
- 3 user led community organisations
- 1 not specified

Level of satisfaction with the event

22% of respondents were extremely satisfied with the event and a further 56% moderately satisfied. Nobody was extremely dissatisfied with the conference and only one person slightly dissatisfied.

Meeting Expectations

22% thought the conference was quite a bit better than they expected and a further 33% thought it better than expected. A further 33% found it met expectations and 11% thought it did not meet expectations.

Organisation of the event

100% of respondents felt that the event was quite or moderately well organised.

Middlesex University as a conference venue

11% thought the venue was excellent and a further 89% rated it as either very good or good.

Quality and variety of presentations

One third thought the presentations were excellent, one third thought they were very good, and a further third thought they were good.

Participation in the workshops

25% felt extremely comfortable with asking questions and joining in with questions. 13% felt uncomfortable and 62% felt either very or quite comfortable in participating in the conference.

Recommendations for the Centre for Co-production

55% of participants were either extremely or very likely to recommend the Centre to a friend and a further 45% were moderately or quite likely to recommend it.

Information about the conference

45% heard of the event through email distribution and a further 22% from NSUN newsletter distribution, and 22% from word of mouth, and 12% via social network sources. No one mentioned the university website or flyers as a source of information.

Additional comments

- I would like to pass on my thanks for the hard work of Prof Ryan, Sarah Carr, Nicola Skinner and the whole team for making it a success especially on such a particularly hot day!
- I think there were some tensions (in the day, but they definitely are in this work more broadly) that I think may have been more productive if they were named. E.g. in our workshop, someone was extremely hostile about survivors being conflated with service users. She had a very important points to make but it really wasn't the time (or the manner) in which it could be heard (she ended up leaving very disgruntled, much to the rest of the group's relief). Another tension is co-production as driven by democratic ideals (participatory) or as theoretically rigorous ("elitist"/seeking particular expertise). Even tensions about where co-production fits with c/s/x leadership (e.g. David spoke of projects being led by survivors, whereas I heard some being super critical of this). I wonder if this diversity were named and explicitly welcomed *repeatedly*, that people may not have felt such a need to defend/declare their position. I could be wrong, of course!
- I very much appreciated the opportunity to meet colleagues and friends old and new and to hear about what service users around Middlesex uni are involved in. And to be alongside you at the start.

I hope that you feel like you have a lot of allies. Though very tired allies this evening!!

- It was great to be at the inaugural event! Thank you for doing it!