2 A critical history of co-production

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‘If mental health service users/survivors are to take charge of our future, then we must also regain control of our past’ (Beresford, 2019b).

This essay offers a history of co-production in mental health in the United Kingdom (UK). By looking at co-production’s origins, we gain a better understanding of co-production now and in the future. There is not one history but many histories so the chapter can only ever be an imperfect account. It examines three elements which have shaped co-production in the UK.

1) Academics and think tanks,
2) The user/survivor movement in mental health,
3) Government policy and legislation.

It is through the interaction of these three elements and the tension between them that co-production in mental health has been formed. In contrast to much that has been written about co-production in mental health, this chapter privileges the user/survivor movement contribution, arguing that it is people who use services who should own co-production.

Defining co-production

Co-production is a slippery concept. There is no fixed definition which everyone uses. The matter is made more complicated and problematic as activity definable as co-production is not described as such by those involved or by the literature. Equally there are instances where something described as co-production is clearly a misuse of the term. So rather than defining co-production at the outset, this chapter discusses the various definitions as we consider how it has been conceptualised.

Co-production in mental health

The British mental health system may seem an unlikely place for co-production to develop. During the period covered in this chapter, the 1970s to the present, the system remains coercive, ordered by a medical model and in thrall to the pharmaceutical industry (Read, 2009; Moncrieff, 2007; Breggin 1993). The power imbalances underlying the mental health system are starker and more dramatic than other areas of health and social care. Treatment choices are very limited. A Healthcare Commission survey in 2008 found that 93 per cent of people in England using community mental health services had been on medication for the past 12 months (Read, 2009: 15). It is hard to find evidence of services fostering self–determination and independence. Detention, seclusion and forced treatment, remain key elements of the British mental health system. The possibility of coercion, the overarchingly paternalistic, risk adverse and medical model approach of most services and the consequent organisational culture are major challenges to developing equal and reciprocal relationships between producers and consumers, a hallmark of all models of co-production (Hyde & Davies, 2004). People who use mental health services also experience appalling rates of

unemployment and poverty. According to the Organisation for Economic Co–operation and Development, in England 'over a third of people with mild to moderate mental health problems, and almost two–thirds of people with more severe mental health problems, are unemployed' (OECD, 2014).

Common sense would suggest there would be little interest in co-production in the mental health sector. However there is a lot of discussion and debate about co-production. For example the 'Five Year Forward View for Mental Health,' includes a commitment to co-production. (Department of Health, 2016). This aspiration has not however been translated into deep and enduring changes to mainstream mental health provision. Co-production has a very long way to go before it is routinely embedded in the design and delivery of services. There are certainly examples of good practice (Skills for Care, 2018) but overall the development of co-production is extremely patchy.

The origins of co-production

It is in the stories of two Americans, Elinor Ostrom an academic economist and Edgar Cahn, a civil rights lawyer, that we find the principal governing narratives of the history of co-production. It is commonly agreed that Elinor Ostrom first used the term co-production in connection with public services:

> The term 'co-production' was coined originally at the University of Indiana in the 1970s when Professor Elinor Ostrom was asked to explain to the Chicago police why the crime rate went up when the police came off the beat and into patrol cars. She used the term as a way of explaining why the police need the community as much as the community need the police. (Stephens, 2008: 9)

Elinor Ostrom describes co-production as '…the process through which inputs used to produce a good or service are contributed by individuals who are not in the same organisation' (Ostrom, 1996: 1,073). This pithy phrase has become a common definition of co-production which is sometimes misused to imply that co-production is happening when, for example, a local authority and a clinical commissioning group work together. However, later in the same paper, Ostrom says;

> We developed the term co-production to describe the potential relationships that could exist between the 'regular producers' (street–level police officers, school teachers, or health workers) and 'clients' who want to be transformed by the service into safer, better educated or healthier persons. (Ostrom, 1996: 1,079)

Ostrom considered 'the term "client" a passive term. Clients are acted upon. Co-production implies that citizens can play an active role in producing public goods or services of consequence to them' (Ostrom, 1996: 1,073).Though Ostrom's work is seen by some as more limited and less radical (Carr, 2018) than what followed, she began describing the process of empowering citizens and providing opportunities for their active participation in service development and delivery. Ostrom argued that following the experience of co-production, citizens develop confidence and networks and often become activists in other areas.

Starting in the 1980s Edgar Cahn, a former staffer for Robert Kennedy, lawyer and anti–poverty activist developed and popularised his own brand of co-production. Through his activities and his book, 'No More Throw–Away People, The Co-production Imperative'(Cahn, 2000), Cahn created his own mythology. Cahn relates how he was in hospital recovering from a massive heart attack. Lying helpless in bed, not knowing if he would live or die, Cahn had an epiphany. He suddenly understood that most social and health systems are based on dependency relationships and this was why they were often ineffective. Through this experience of uselessness, Cahn developed his theory of co-production which builds upon the ideas of Elinor Ostrom.

Cahn put his thinking into practice by developing a non–monetary exchange system he called 'Time Dollars'. Time Dollars enabled people to exchange an hour of their time with an hour of someone else's. Everyone's time was valued equally and through the system of credits, people could exchange with anyone in the network. Time dollars as Cahn himself said were only a tool (Cahn, 2000); the real invention was his approach to co-production.

Cahn's theory of co-production is built around the 'Core Economy'. In contrast to the market, the Core Economy consists of the work and support provided by family, friends and community members which is not valued in monetary terms.

> Family, neighbourhood, community are the Core Economy. The Core Economy produces: love and caring, coming to each other's rescue, democracy and social justice. (Stephens, 2008: 5).

Cahn argues that co-production has three aspects: firstly, it recognises the Core Economy as having '…parity with the world of money and market in which professionals live' (Cahn, 2000: 31).

> Second, Co-production is a process…It may be smooth and cooperative or it may take the form of a dialectic that yields parity, only after a struggle because the process entails a shift in status that maybe embraced or resisted.
>
> Finally, Co-production is a set of standards or goals: an asset perspective, redefining work, reciprocity and social capital. (Cahn, 2000: 31)

For Cahn, co-production clusters around these overlapping concepts; an asset–based approach is about acknowledging that everyone has something to contribute. Reciprocity is about mutual benefit or, in more simple terms, 'a two–way street is better than a one–way street' (Cahn, 2000: 32).

Permeating Cahn's approach is his insistence that co-production is about social justice. Co-production is an imperative which demands 'No more free rides for the market economy extracted by subordination, discrimination and exploitation', an end to devaluing people and profiting from their troubles and 'no more disinvesting in families, neighbourhoods and communities' (Cahn, 2000: 29).

People with mental health issues appear infrequently in, 'No More Throw–Away People'. However, Cahn uses 'the Story of George' to illustrate the power of reciprocity. George, who

is not dignified with a surname, is described as 'a gentle soul', 'a schizophrenic with nearly 19 years of residential and outpatient treatment... at an institution for the mentally ill' (Cahn, 2000: 143). Unable to sustain employment, George finds using public transport and getting out of bed difficult and is happiest grooming horses. Cahn explains how in exchange for legal support, George was asked to help distribute food at a Time Dollar warehouse. Cahn emphasises George's delight that he could be useful to his lawyer. George is ideal for his role at the food bank which involves hard manual labour, as he has the 'build of a weight lifter'. While this story is presented as a fable of reciprocity, it is no fairy story for George. His role in the story appears to be as a grateful supplicant rather than equal partner. The way Cahn describes him verges on patronising and many people who use mental health services would not want to be defined as 'a schizophrenic'.

'No More Throw–Away People' is a strange hybrid, part how–to guide, part thesis; it is also an autohagiography and a call to action, using stories, poetry and biblical quotations to exhort and inspire. Despite its contradictions or perhaps because of them, 'No More Throw–Away People' and Cahn himself have had a profound impact on the development of co-production in the UK.

Development in the UK

In the late 1990s, the New Economics Foundation (NEF) thinktank, supported by the National Endowment for Science, Technology and the Arts (NESTA) introduced the Cahn Model of co-production to the UK. NEF formed strong links with Edgar Cahn and were instrumental in setting up several Time Dollar services which they re–named Time Banks. The most well–known of these was established in 1998 by Rushey Green, GPs' surgery (Rushey Green Time Bank, 2018). One of this Time Bank's aims was to address the isolation of people who were depressed.

NEF developed Cahn's approach to co-production and published in 2008 a Co-production Manifesto, for which Cahn wrote a foreword (Stephens, 2008). In 2010 NEF published, 'Public Services Inside Out', which took Cahn's four core values of co-production (Cahn, 2000: 24), added two more and adapted them to the context of UK public services (Boyle et al, 2010). NEF presented the principles as six ingredients required by a co-production project. Each of their chapters focusses on a specific ingredient. They are listed on the contents page as:

> Building on people's existing capabilities
> Mutuality and reciprocity
> Peer support networks
> Blurring distinctions
> Facilitating rather than delivering
> Recognising people as assets (Boyle et al, 2010: 5).

These principles are often quoted in co-production mental health guides, frameworks and toolkits, for example Skills for Care (2018: 14), which have proliferated in recent years. Many organisations have developed their own principles which draw on, add to, expand or collapse NEF's original six. The Social Care Institute for Excellence has four co-production

principles (Social Care Institute for Excellence, 2015) and the Coalition for Collaborative Care has five values and seven steps (Coalition for Collaborative Care, 2019)
NEF also developed a definition of co-production;

> A relationship where professionals and citizens share power to plan and deliver support together, recognising that both have vital contributions to make in order to improve quality of life for people and communities.
> (Social Care Institute for Excellence, 2015: 7)

The user/survivor movement in mental health

In the next section, I consider and contrast the mental health user/survivor movement's contribution to shaping co-production with the approach of think tanks such as NEF.

Through its publications and activities, NEF provided a theoretical framework for co-production in mental health in the UK. However, despite NEF's calls for more equal relationships, reciprocity and the development of peer networks; their writing and practice largely ignored the burgeoning movement of people who use mental health which had been gaining strength since the 1970s. For example, *Co–production: A manifesto for growing the core economy* (Stephens et al., 2008: 7) describes the South London and Maudsley NHS Foundation Trust (SLaM) as 'innovative'. This is despite SLaM's core activity being running a statutory mental health service which includes the traditional mix of psychiatrist led, acute wards and community mental health teams. As evidence of SLaM's innovative approach and in a strange echo of Cahn's 'Story of George' the Manifesto provides the example of Bee Harries (Stephens, 2008: 7). Ms Harries, is a local mental health service user who received an individual budget and was also enabled to become involved in a network through which she is part of a poetry writing group. However, Ms Harries is mostly a passive voice in the Manifesto. She has one short direct quote in which she says that, 'our life does not have to be going from one drop–in centre to another'. The rest of the text frames Ms Harries' experience as an example of the benefits of co-production, mutuality and reciprocity in language it is unlikely she would have used herself. Contrast this with the Manifesto's description of Zoe Reed, then Director of community services at SLaM, as one of 'a growing band of prophets of co–production'. The other prophets listed are all senior professionals and academics.

Despite the Manifesto authors' interest in peer support networks, which they say 'are the best means of transferring knowledge and capabilities' and their wish to '[devolve] real responsibility, leadership and authority to users' (Stephens, 2008: 12–13), they appear blissfully unaware that Southwark Mind, a user–run, user–led local Mind association has been operating within SLaM's area for over 10 years. As a user–run organisation, Southwark Mind's concerns and activities reflect the unfiltered voice of local people who use mental health services. In 2008/9, their activities included running a women's forum, setting up self–help groups for parents and for people who hear voices and initiating a project in collaboration with SLaM to involve users in the evaluation of services. Southwark Mind was also involved in 'a long and bitter campaign' to re–instate a South Asian only drop–in service. In addition, Mind continued to run Southwark User Council, which seeks to present the views of local people who use services to senior leaders (Southwark Mind, 2009).

Southwark Mind is part of a national movement of people who use mental health services:

> The 'service user/survivor movement' is a term used to describe the existence of numerous individuals who speak out for their own rights and those of others, and local groups and national organisations set up to provide mutual support or to promote the right of current and former mental health service users to have a voice (Wallcraft, et al., 2003: 3).

The movement is a broad church with common concerns including calls for less medicalised and coercive services, alternatives to medication, greater availability of advocacy and ending societal discrimination (Wallcraft, et al., 2003).

The UK user movement emerged in the 1970s with the formation of local Mental Patients Unions in Manchester, Portsmouth and the London borough of Hackney. In 1978, Judi Chamberlin an American 'ex–mental patient' published 'On Our own' (Chamberlin, 1988) setting out the case for patient–controlled services. Chamberlin argued passionately for a patient–controlled alternative to bio–medical psychiatry. She maintained that because the power differentials were so significant between professionals and people who use services, collaboration would not bring about change.

This tension still exists within the user/survivor movement between those who believe the focus should be on developing user–controlled self–help services and those attempting to reform the current system through collaboration with professionals. 'Stopovers on my way home from Mars' (O' Hagan, 1993), is a study of the international mental health user movement, including the UK, by a New Zealand user/survivor. It is full of warnings of the dangers of collaboration;

> When we fail to link our experience with our ideology and ideology with our practice we are no longer a powerful force for change. Instead we tend to parody the system that has dehumanised us. (O' Hagan, 1993: 81).

The UK user/survivor movement perhaps needs to take particular note of such cautions as its history has tended to emphasise the development of collaborative rather than user-controlled services. Starting in the 1980s, collaboration between service users and professionals began to be called user involvement. Local user groups were funded, and in some cases set up by local authorities, with the explicit intention that they would become involved in the design and evaluation of services. It was not until relatively recently that this activity became referred to as co-production. However, user involvement fits well with most if not all of the NEF and Cahn's typographies of co-production. It is undoubtedly an example of Ostom's regular producers working with clients.

The user movement entered a new phase of more significant organisation and effectiveness in the late 1980s. In 1986 Peter Campbell founded Survivors Speak Out (SSO). SSO was a radical network of user/survivors which organised events and produced publications including Mary O'Hagan's 'Stopovers On my way Home from Mars'(O' Hagan, 1993). Jan Wallcraft became the first staff member at MINDlink, national Mind's internal network of user/survivors. Her appointment was the result of a deliberate decision to employ a user/survivor co–ordinator. In 1992, the United Kingdom Advocacy Network (UKAN) was set up with a membership of more than 100 local survivor groups.

During the 1990s there was increasing awareness about the over–representation of ethnic minority people in the mental health system and concern that white people dominated the

user movement (Wallcraft, et al., 2003). Several black and ethnic minority user groups formed. For example, in 1998 SIMBA (Share In Maudsley Black Action), the Black Patient/User/Survivor group was established (Survivors History Group, 2019). Some users and survivors liken the movement to the struggles for women's and black liberation (Wallcraft et al., 2003).

During the early years of this century, the user/survivor movement continued to grow and develop. However, it was during this period that both SSO and UKAN struggled to secure funding and became less effective. In 2003, 'On Our Own Terms' (Wallcraft, et al., 2003), a review of the user/survivor movement, was published. It articulated concerns about the effectiveness of user involvement and argued for more training and resources for both professionals and users to address power issues. It expressed concern around how user/survivors were valued and compensated for their involvement. The report also recommended setting up a national user/survivor network. In 2007, following a user/survivor conference, Doing it Ourselves, the National Survivor User Network (NSUN), a new national network was set up with funding from two grant giving trusts (NSUN 2020). NSUN trod a delicate path which reflected the general development of the British user movement. NSUN engaged with government, undertaking joint projects such the 4PI standards for involvement but also remained an independent user-controlled organisation which campaigned fearlessly on issues such as the review of the mental health act (NSUN 2020). By 2017, NSUN had 4,500 individual members and was in touch with 100s of user–led organisations. However, the years of government austerity from 2008 have devastated the user movement. In 2018, NSUN reported that 117 user–led groups had closed over an 18–month period (NSUN, 2018).

The user movement has made an enormous contribution to the development of co-production in the UK. This has not always been acknowledged by other key stakeholders. This is partly because of the separatist current that still runs through some local and national organisations and because, until recently, users and survivors did not call their activities co-production. For example, when in 2013, NSUN originally developed their '4PI National standards for the meaningful involvement of people who use mental health services, their family and carers', the original documents did not use the word co-production (NSUN, 2013). However, 4PI is now referred to on NSUN's website as being about 'ensuring effective co-production, thus really improving experiences of services and support' (NSUN, 2019).

Perhaps the most valuable contribution the user/survivor movement has made to the development of co-production in the UK is a realistic understanding of the efforts that need to be made to truly equalise power differentials if co-production is to be meaningful. Sarah Carr a user/survivor researcher and Co–Chair of NSUN develops this argument;

> While the stated aim is to 'improve patient experience', there is no real analysis of how and why the health (in particular the mental health) system 'declared people useless'. In the UK health think tanks reports there is talk of 'patient leaders' having collaborative relationships' with clinical or managerial leaders but without close consideration of the fundamental power realignment, preparation, facilitated personal reflection and individual role renegotiation that needs to occur before this is possible. (Carr, 2018: 79)

So big questions remain about the impact of user involvement and/or co-production. Is it possible for truly equal and reciprocal relationships to develop between user/survivors and professionals especially given the dominance in the mental health system of the bio-medical model? Does the practice of co-production further disguise rather than reveal the reality of power relations? Without a social model understanding of their experiences in the system and strong roots in the user movement how can individual user/survivors collaborate with professionals as genuinely equal partners? Herein lies a fault line between the NEF/Cahn model of co-production and the user/survivor movement. The movement is diverse, however there is a consistent critique of the medical model and the slow emergence of a fundamentally different approach to mental health based around an understanding of the impact of trauma and structural inequality and a desire for self-determination and liberation. Despite assertions about co-production needing to be linked to social justice, a specific critique of the mental health system is lacking from NEF's account. NEF seems to be arguing that if everyone worked together services would improve and that this can happen without any real change in the ideology, power relations or culture of the system.

Legislation and policy that supported co-production

Citizen participation in health and social care services can be seen as a phase in the development of democracy and human rights commonly found in western democracies. It is important to understand user involvement and co-production policy in this context as part of a historical continuum which starts with the development of universal suffrage and fundamental rights. However, the promotion by the state of greater citizen participation has occurred during a period of neo–liberal dominance of social policy. As a result, progress around user involvement/co-production has coincided with cutbacks in public services and welfare provision. So whilst ideas and discourses around citizen rights and participation have grown, at the same time some basic services have been withdrawn and certain fundemental liberties curtailed. (Beresford, 2019a).

Since 1961, when Health Minister Enoch Powell made his famous Water Tower Speech, UK mental health policy and legislation has steadily given greater emphasis to the rights of people who use mental health services including influencing the shape of services. This gathered pace with the National Health Service and Community Care Act (1990), which began the development of Care in the Community. The Act also made consultation with service users a legislative duty for local authorities. In 1991, the Mental Illness Specific Grant (MISG) was introduced (Barnes, 1993). The MISG allowed local authorities to support local mental health user groups. As a consequence of the Community Care Act 1990 and the MISG, by 1992, more than a hundred local user/survivor groups existed across UK (Survivors History Group, 2019).

In 1992, the Mental Health Task Force Service User Group (part of Department of Health's Mental Health Task Force) was set up. The Task Force ran a series of regional service user conferences and produced publications: guidelines for service user charters and advocacy. Although the User Group was not described as such, it was arguably an excellent example of co-production in which people who use services, professionals and policymakers worked together. Representatives of the three main working groups; MINDlink, SSO and UKAN sat on the Task Force and organised regional events (Survivors History Group, 2019). In 1999, the Department of Health, published, 'A National Service Framework for Mental Health' which committed to involving users and carers including from black and ethnic minority groups in service development, monitoring, and staff training (Department of Health, 1999).

From 1999 to 2007, policy and legislation continued to support the involvement of people who use services and the public. In 2000, *The NHS Plan* included a requirement for Patient and Public Involvement Forums to be set up in every NHS trust and primary care trust in England (Department of Health, 2000). The aim was for these forums to allow local people an active role in decision making. Despite policy setbacks to the growth of service user involvement such as the 2001 abolition of Community Health Councils (which had often served as incubators for user groups), the user/survivor movement continued to grow and have an impact on services.

The review of the 1983 Mental Health Act, which started in 1999, resulted in the introduction of Community Treatment Orders in 2007. This was a major defeat for the user movement as it extended the powers to force people to adhere to treatment regimes after their discharge from hospital. More positively, the 2007 review included restrictions on the use of electric convulsive therapy and introduced statutory rights to independent mental health advocacy. Despite these progressive measures the outcome of the review of the 1983 Mental Health Act demonstrates the limitations of the influence of people with mental health issues on policy at the highest level.

In 2007, co-production is first mentioned in government policy. The *Putting People First* concordat proposed that the transformation of adult social care services toward a more personalised approach would 'be the first public service reform programme which is co–produced, co–developed, co–evaluated and recognises that real change will only be achieved through the participation of users and carers at every stage.' (Department of Health, 2007: 1). *Putting People First* policymakers recognised that, to coproduce, users and carers would need their own local organisations which could develop a collective vision for local services and co–ordinate individual contributions. Local authorities were strongly encouraged to ensure that they developed and sustained User–Led Organisations. The Department of Health's 'Local Authority Circular No.1' (2008: 25) said: 'Where user led organisations do not exist, a strategy to foster, stimulate and develop these locally should be developed'. Also, a programme to support and strengthen User–Led Organisations was set up at the Office for Disability Issues (Social Care Institute for Excellence, 2010).

In 2009, the Cabinet Office published 'Co-production in Public Services, A New Partnership with Citizens'. This discussion paper defined co-production as 'a partnership between citizens and public services to achieve a valued outcome' (Horne & Shirley, 2009: 3). It argued that co-production should be central to the improvement of all public services. It outlined changes needed to support co-production. These included control of budgets being given to users and front–line staff and backing for peer support. It recognised the need for changes to professional training and culture.

The statutory guidance of the Care Act 2014 is the first time that co-production is defined in legislation:

> "Co-production" is when an individual influences the support and services received, or when groups of people get together to influence the way that services are designed, commissioned and delivered (Department of Health, 2014: 17).

This definition is seen by some commentators as weak, mainly because of the use of the word 'influence'. (Social Care Institute for Excellence, 2015). The guidance also suggests that co-production should be used to develop local implementation strategies, information and advice plans, to design preventative approaches, conduct individual assessments, shape markets and create mutual support networks.

The *Five Year Forward View* for mental health published in 2016 argues for embedding co-production within the design and delivery of services.

> Co-production with clinicians and experts–by–experience should also be at the heart of commissioning and service design, and involve working in partnership with voluntary and community sector organisations. (Department of Health, 2016: 25)

Conclusions and looking to the future

> Movements often have radical and ideologically strong beginnings but as they grow they tend to moderate and lose clarity (O' Hagan, 1993: 81).

There is a clear risk that the current fashion for co-production rather than strengthening the capacity of the user/survivors to engage as equal partners in the design and delivery of services, it is a site of co-option and dilution. For example a 2019 paper describes its aim as;

> To co-produce consensus on the key issues important in educating mental health professionals to optimize mental health medication adherence in Black, Asian and minority Ethnic (BAME) groups. (Gault 2019: 813)

Its hard not to be outraged that a co-production approach could be taken to the issue of medication adherence for BAME groups. Especially given all the evidence that BAME users are more likely to be medicated and less likely to be given talking treatments (Bignall, 2019). But what such developments show is that in order to be a real force for change co-production needs to integrate the values of the user/survivor movement and incorporate a critique of the medical model.

In 2013,The Social Care Institute for Excellence (SCIE) published 'Co-production in Social Care: What It Is and How to Do It' (SCIE, 2015). The process of developing the guide was highly co–productive, including a user–led steering group and authors with lived experience of mental health issues. The guide attempts to combine policy, academic work and knowledge generated by people who use services. It proposes four co-production values: Equality (power–sharing), Diversity, Accessibility and Reciprocity. These values draw upon both the Cahn/NEF model of co-production but also incorporate the concerns of the disability and user/survivor movements around power, accessibility and diversity.

The history of co-production delineates the steady acceptance of the idea that the citizen has a role in improving outcomes in mental health. However government and the sector struggle to turn policy aspirations into services that truly foster equal and reciprocal relationships between people who use services and professionals. The history of co-production is also the history of the user/survivor movement which has liberation at its heart. It is only by insisting

that co-production itself must be co–produced and co–owned by user/survivors, that the promise of co-production can be fulfilled.

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