Are mainstream mental health services ready to progress transformative co-production?

NDTi

National Development Team for Inclusion

'Somebody has got to say,
"Stop! Wait!
Forget the catchy words.
There's a big gaping hole
in this boat we call
the mental health system
and we are all
going down with it!"

(Deegan, 1987 p.9)

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**'I participate, you participate,
he participates, we participate,
you participate...they profit.'**
(quoted in Arnstein, 1969)

Co-production in mental health is about progressing 'the transformation of power and control'. It requires thinking about people, power, partnerships, resources and risk in ways that are very different to what has gone before in mental health services. It implies relocating power to mental health service users, survivors, their organisations and communities.

The way co-production is done is specific to the task, situation and the people involved and can be large or small scale. There are a set of core values and principles, but there is no single, universal technique.

Co-production is not determined by what the professional or service wants but focuses on the equal contribution of service users and communities. To ensure full collaboration, the co-production process should be about achieving equality and parity between all those involved.

Edgar Cahn's (2004) original co-production core values demand that those using services have equal power and influence, and full recognition of their assets and expertise as having equal value to those of practitioners. His foundational view of co-production is about social justice and inclusion, with the fundamental conviction that there should be 'no more throwaway people' because everyone has assets, strengths and contributions to make.

Depending on the context, transformational co-production may be collaborative, but it can also involve challenge. Large or small-scale change through transformative co-production can mean 'hell-raising' and challenge is a necessary part of the process.
Progressing transformative co-production may be challenging in a mental health system that retains significant traces of 'the institution' and its history of the control, detainment, isolation, segregation, pathologisation and medicalisation of people with mental health problems.
Literature on service user and survivor mental health reform and revolutionary concepts such as personal recovery, mental health service user participation, direct payments and user-defined empowerment has shown that there may be specific challenges for achieving transformative co-production in current mainstream NHS mental health services.

Evidence on personal recovery and direct payments shows there is a risk that co-production may be absorbed into and defined by mainstream mental health organisations and become part of institutionally or professionally defined procedure.

The research on personal recovery, mental health service user participation and choice and control through direct payments shows that their potential progress transformative co-production can also be significantly limited by institutional control. This includes restrictions on service users exercising their agency and power and through the maintenance of professional or service power and agency.

Institutional control in the form of traditional rules and roles can negatively affect the way practitioners can work equally and collaboratively with service users, as they can feel trapped in restrictive professional roles.

However, transformative co-production is about dismantling institutions, changing their cultures and practices and rebalancing power. It means disrupting traditional fixed roles and power relations between professionals and service users and should not be solely determined by the institution or organisation.

From the evidence on recovery, mental health service user participation, direct payments and user-defined empowerment, mainstream mental health services may find progressing transformative co-production challenging.

There are distinct challenges for co-production in mainstream NHS mental health services which relate to institutional

- resistance to change
- restrictive administrative procedure and professional practice
- avoidance of challenge, confrontation or emotional expression
- the demand to conform by institutional rules and cultural norms

If given facilitated space to meet and open up dialogue outside the restraints of the institutional characteristics of mainstream mental health services, service users, survivors and practitioners could develop common values, aims and more open, co-productive relationships.

Introduction and aims

This position paper is aimed at everyone with an interest in understanding the challenges for progressing co-production work in mental health services. It is particularly designed for those involved in mental health policy and development as well as service users and practitioners who want to engage with and understand transformative co-production in mental health.

It looks at the implementation of service user and survivor reform and revolution concepts in mainstream mental health services, to assess how ready mainstream mental health is for 'transformative co-production'. It identifies a number of unique challenges and sets out some key issues for co-production in mainstream mental health services.

This paper has been written in response to the recommendations of a collaborative working group of mental health service users, carers, practitioners and policy-makers.

Transformative co-production is:

'a potentially transformative way of thinking about power, resources, partnerships, risks and outcomes, not an off-the-shelf model of service provision or a single magic solution'. *(Needham and Carr, 2009, p1)*

'the transformation of power and control'
(Slay & Stephens, 2013 p.?)

The main questions being explored are:

- Do mainstream mental health services currently offer the right conditions for transformative co-production?

- What does evidence from mental health service user and survivor reform and revolution concepts suggest needs to be accounted for and addressed when doing co-production in mainstream services?

This paper builds on the New Economics Foundation and Mind report 'Co-production in mental health: A literature review.' It examines some of the existing evidence on the barriers and facilitators to previous attempts by service users and survivors to achieve the transformation of mental health services.

It uses the ideas of pioneering mental health service users and survivor activists to assess what the current conditions are for co-production.

The main mental health service user and survivor service reform ideas discussed are:

- Empowerment
- Personal recovery
- Service user and survivor participation
- Direct payments

This paper aims to examine co-production from a perspective of mental health service users, survivors and their organisations. It is written by someone with lived experience of mental distress and mental health service use. To anchor the exploration, the paper revisits the original core principles of co-production to contextualize and assess the evidence being examined.

The paper also aims to explore what one collaborative discussion group member called 'the dark matter' often challenging co-production and collaborative working between service users and practitioners in mainstream NHS mental health services.

The findings informed the framework of questions used for gathering practice for the guide that accompanies this position paper.

Background

This project builds on earlier work undertaken by the New Economics Foundation (NEF) and Mind that highlighted the need for transformative co-production in mental health (Slay & Stephens, 2013), and a subsequent informal survey of interested stakeholders conducted on social media.

NEF and Mind analysed some of the literature and practice relating to co-production and mental health for the UK and identified the following themes from the evidence:

- Improved social networks and social inclusion, including feeling valued, community cohesion, reduced stigma and reduced isolation.

- Addressing stigma of mental health service use through developing peer and support networks and blurring boundaries between people using the services and those working in them.

- Improved skills and employability, including improved knowledge and engagement with formal learning and training opportunities, and longer-term employment outcomes [such as finding and retaining meaningful paid employment].

- Prevention, including the decreased use of acute mental health services and a reduction in severe, acute mental health needs, at individual and system level.

- Improved mental and physical well-being, with the two domains of 'personal resources' and 'functioning and satisfaction of needs' strongly linked.
                                    (Adapted from Slay and Stephens, 2013)

The social media survey of interested mental health stakeholders (including practitioners, service users, policy professionals and providers) identified two major barriers to co-production being widely adopted, namely

- a lack of understanding of the concept in mental health specifically

- the lack of engagement from people managing and/or delivering mainstream mental health services.

As a result of this preparatory work, the National Development Team for Inclusion (NDTi) received funding from the Esmée Fairbairn Foundation for a collaborative project to demonstrably increase understanding of co-production in mental health. A collaborative working group of service users and their organisations, carers, practitioners, policy and research experts was established to:

- Explore the unique challenges for and responses to co-production in mental health services.

- Develop a practical, evidence-based resource on how co-production can be understood and implemented in mental health.

The collaborative discussion group wanted the position paper to consider co-production within

statutory mainstream mental health services. They recommended writing a position paper that examines the research evidence and outlines some of the specific challenges as well as:

(a) highlight what these particular challenges are,
(b) provide a clear basis for the position from which the collaborative project is working and
(c) an evidence base from which to develop the accompanying practice guide

The collaborative working group and initial survey indicated that definitions of co-production have been determined by policymakers, with few frontline or service user lived experience perspectives.

The group also identified an issue with frontline staff, innovative mental health projects and user-led organisations not owning or shaping what co-production means for mental health.

Why mental health?

Over the years mental health care has been subject to many ongoing debates across different disciplines about its fundamental practices and philosophies, reflecting the legacy of institutionalisation and social control (Porter, 1987). Mike Clark has observed that, for mental health, co-production is:

> 'clearly a part of a long running attempt to fundamentally shift the debate about mental health care, like that of community care and recovery before it' (Clark, 2015)

Much of the policy and practice discussion on co-production has been generic to health and social care and led by academics and policy makers, rather than by those at the frontline, particularly service users themselves. However, mental health services and service user and survivor experiences have unique characteristics that potentially make mainstream mental health service transformation through co-production particularly challenging.

The following quotes sum up some of the core factors that make mental health distinct from most other long-term conditions:

> '…mental health services differ from physical health services in a number of discrete ways. Distinguishing features include a unique service history founded on aspects of containment and compulsion, the need for care teams to accommodate a greater multiplicity of service user experiences and the entrenched stigmatisation of those using mental health services.'
> (Bee et al, 2015).

> 'The problems confronted by people who experience mental disorders are often conceptualised in terms of health and illness. However, these problems extend far beyond the healthcare system, into all areas of human life. Having a psychiatric diagnosis may have a negative impact on every aspect of the individual's life, leading to the deprivation or limitation of rights in relation to housing, employment, and family life.' (Prior, 2007).

An understanding of these particular factors will help those attempting to undertake co-production in mainstream mental health services. Fundamentally, co-production principles demand that those using services attain equal power and influence, and a full recognition of their assets and expertise as having equal value to those of practitioners. However, this will be challenging in a mental health system that retains significant traces of the history of the control, detainment, isolation, segregation, pathologisation and medicalisation of people with mental health problems (Porter, 1987; Beresford, 2009; Beresford et al 2016).

Unlike any other 'illness' or long-term condition, there is a law (Mental Health Act 1983/2007) that means that people who experience extreme mental distress can be legally detained and subjected to compulsory treatment. So while much co-production literature talks about 'citizenship', the legal and medical controls imposed on people with mental health problems can make full citizenship difficult to conceive of and exercise (Arrigo et al, 2011; Prior 2007).

Stigma, discrimination, shame and social shunning (including within mental health services) are such big problems for people with mental health problems (Thornicroft, 2003) that there is a specific UK government funded anti-stigma and discrimination programme (Time To Change, 2008).

Over-reliance on pathologisation and clinical diagnostic categories to classify mental health problems continue to mean that understandings of 'madness' gained through lived experience and social models of mental distress as response to trauma, deprivation, abuse or discrimination have not achieved equal status to that of medical explanations (Beresford, 2009; Kalathil, 2011; Beresford et al 2016).

Historically people with mental health problems have been feared, thought to be deviant or morally defective, and risk is still a factor driving practice in mainstream services (Thornicroft, 2003; Morgan, 2004; Grove, 1982): 'their processing in the psychiatric system is related not only to them being seen as defective, but also frequently dissident, non-conformist and different in their values' (Beresford, 2009). This, along with stigma and pathologisation, has made achieving credibility and equal status for service user and survivor knowledge and experiential expertise very difficult (Beresford, 2003).

These are important considerations for undertaking co-production in mainstream mental health. There are particular power and fixed role dynamics within the psychiatric system itself and between practitioners and service users, especially in the context of the Mental Health Act 1983. These role dynamics can result in loss of agency and dependency.

Mental health services have a relationship to the forms of stigma mental health service users and survivors can experience in wider society (Thornicroft, 2003). Historically, the system has influenced how people with mental health problems are negatively perceived as somehow 'morally defective', 'other' or 'deviant' (Grove, 1982). From a service user and survivor perspective, negative uses of power and control remain defining features of mainstream mental health services and yet co-production is explicitly about progressing 'a transformation of power and control'.

The concept of co-production originated in the USA during the 1970's and 1980's with the political economist Elinor Ostrom and the law academic and activist, Edgar Cahn.

Ostrom and her colleagues were struggling with the fact that the bureaucratization of police services had resulted in an increase in crime in a particular urban area. They found that officers were in cars rather than 'on the beat', and as a consequence had become detached from the people on the street who were valuable sources of knowledge and expertise. They concluded that the quality of the relationships between service providers and service users or citizens were of primary importance, with services relying as much on the knowledge and expertise of users as professionals:

> **'We developed the term 'coproduction' to describe the potential relationships that could exist between the 'regular' producer (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. Coproduction is one way that synergy between what a government does and what citizens do can occur.'** (Ostrom, 1996, p1079)

Edgar Cahn's 'universal core values of co-production', from his book 'No More Throwaway People' (Cahn, 2004) are consistent with the values of the mental health service user and survivor movement. Cahn's thinking has been highly influential to the way co-production has been conceptualized in UK health and social care policy, but the radicalism of his original ideas seems to have been diluted with each policy or service-centred interpretation. Cahn's articulation of co-production as being about social justice and having broader social and political applications beyond service reform reflects the values and understandings of many mental health service users and survivors who get involved in activism, participation initiatives and user-led organisations (Beresford and Carr, 2012; NSUN 2015).

It requires 'transformative level co-production', meaning a relocation of power to mental health service users, survivors, their organisations and communities (Needham & Carr, 2009). In their report on co-production in mental health, the New Economics Foundation and Mind state that transformative co-production is what is required in mental health as it is about

> **'the transformation of power and control'.**

Cahn's universal core values of co-production are radical and demand a fundamental critique and challenge of the way public services are run. They are particularly challenging for mainstream, clinical mental health services. Importantly, Cahn situates co-production as a means to work for social justice and the four universal core values are:

- **'An asset perspective: "no more throwaway people"**
- **Redefining work: "no more taking the social contribution of people for granted"**
- **Reciprocity: "stop creating dependencies and devaluing those whom you help while you profit from their troubles"**
- **Social capital: "no more disinvesting in families, neighbourhoods and communities".'**

(Cahn, 2008, p31)

Cahn also outlines some of the fundamental building blocks for supporting the four core values of co-production. These can form a framework for assessing the existing evidence on what has happened to service user and survivor led reform in mental health services, especially mainstream clinical services:

- **It is a construct – a framework of participation to support the four core values that is not determined by what the professional wants but supports the equal contribution of the service user/citizen/community.**
- **It is a process – a process that achieves parity between the professional and the service user/citizen/community. According to context, the process might be collaborative, co-operative or confrontational.**
- **It is a set of standards – the 'universal core values' of an asset perspective, redefining work, reciprocity and social capital. These are 'the litmus test against which the integrity and authenticity of the effort is judged' (ibid p.31)**

Using the core values as a baseline set of standards, Cahn maps out what co-production means on both an individual and societal level.

On an individual level he recognizes that 'we all need to be needed regardless of age, formal credentials, marketable skills or barriers. Co-production 'entails the fulfilment of that need [where] one's contribution is acknowledged, recorded and externally validated' (ibid p.34). He also acknowledges that seeking support should not result in dependence, but rather interdependence.

Cahn recognises that 'individuals are embedded in social contexts'. For societal co-production, he sees a shift in relationships between professionals and service user/citizens or communities which moves from 'one of subordination and dependency to parity, mutuality and reciprocity' (ibid p.35). He argues that on a societal level, co-production has the potential to alter 'the conventional distinctions between producers and consumers, professionals and clients, providers and recipients, givers and takers' (ibid p.35).

Finally, he recognises that such radical change requires disruption and that

> **'hell-raising is a critical part of co-production' (Cahn 2008 p4).**

Consistent with the values and aims of the mental health user and survivor movement, Cahn's original conception of co-production is radical and has values rooted in social justice. Its demands and challenges reach beyond services and pose a challenge to society itself and the wider values placed on different people, contributions and achievements.

Learning...
from the mental health service user reform and revolution

'[psychiatric services] squeeze the resourcefulness out of mad people, their families and communities'
(O'Hagan, 2014, p.?)

This section scopes out a body of evidence on the implementation of some key radical mental health service reform and revolution concepts originating with service users and survivors that arguably reflect co-production core values and building blocks, as defined by Cahn.

In order to identify some of the central challenges, it is useful to look at evidence on what has and has not worked in the past for power sharing, participation and change for mental health service users and survivors and the ideas of service user and survivor activists. This can provide fundamental insights into what the present conditions are for co-production in mainstream mental health services, crucially from the perspective of those with lived experience of mental distress and service use.

Empowerment in mental health

'Empowerment' is a term that has become so embedded in professional language its original definition by service users and survivors has been obscured. However, empowerment is very relevant to understanding what co-production can mean for mental health and social justice.

In 1997 a team of American academics and survivors (including Judi Chamberlin, a founder of the psychiatric survivor movement in US) developed a 'consumer constructed scale to measure empowerment among users of mental health services' (Rogers et al, 1997). The authors say that the service user and survivor determined scale offers a 'framework for a clearer understanding of the imprecise and overused concept of empowerment' (ibid p.1042), and so were addressing a situation similar to that with co-production in mental health currently.

The research revealed five core factors relating to empowerment, as follows:

1. Self- efficacy/self-esteem
2. Power/powerlessness
3. Community activism
4. Righteous anger
5. Optimism/control over future

What is notable is that the authors highlight elements that are also central to transformative co-production, as originally defined by Edgar Cahn. Most strikingly the results of the research suggest that programmes seeking to promote 'empowerment' must focus on the five identified factors, including 'righteous anger' and

'they must also focus on heightening sociopolitical consciousness and community activism' (ibid p.1046).

So it can be argued that 'empowerment', as defined by mental health service users and survivors, shares core aims and values with Cahn's radical idea of co-production. Achieving

empowerment may mean becoming angry or disruptive as part of the transformative process, or as Cahn puts it, 'hell-raising.'

According to Rogers, Chamberlin and colleagues, becoming empowered also entails community activism, the disruption of traditional roles between service user and practitioner and challenging the misuse of power in mental health services.

Recovery in mental health

Recovery is a concept that originated within the mental health service user and survivor movement, but has become increasingly absorbed into mainstream mental health services and professional practice. Like empowerment and co-production, it is also something mental health services have found 'difficult to define' (Le Boutillier et al, 2015).

Recovery was originally conceived by people with lived experience of mental distress as hope for recovering a life and personhood after a mental health crisis and psychiatric service use characterised by dependency, despair, 'us and them' relationships and powerlessness (Deegan, 1987).

One of the originators of the recovery concept, US survivor and disability-rights advocate Patricia Deegan was clear about the radical disruption needed in order to create a culture of hope in mental health services where people could begin to recover themselves,

'First we must be committed to changing the environments that people are being asked to grow in. We must recognize that real change can be quite uncomfortable and sometimes I worry we will content ourselves with superficial change.' *(Deegan, 1987 p.9)*

Deegan outlined ten key questions for mainstream mental health practitioners and providers to reflect on as part of assessing environments in which people can grow and recover their lives and identities following a mental health crisis. Many of these fundamental questions are consistent with those that should be asked of co-production in mental health:

- 'Do we understand that people with psychiatric disabilities possess valuable knowledge and expertise as a result of their experience? Do we nurture this important human resource?
- Have we created environments in which it is possible for staff to be human beings with human hearts?
- Do we work in a system which rewards passivity, obedience and compliance?
- Have we embraced the concept of the "dignity of risk" and the "right to failure"?
- Are there opportunities within the mental health system for people to truly improve their lives? Are there a range of affordable, normal housing situations from which people can choose a place to live? Is there work available?'
(Adapted from ibid, p. 10-11)

Since it was conceived by those with lived experience as a revolutionary way to reconceive mental distress and responses to emotional crisis by and for people who experience them, 'personal recovery' has become integrated and absorbed into mainstream mental health services. Some argue that it has lost much of its original power and aims, as it has been co-opted into clinical mental health services in various ways as well as into professional and policy terminology (Slade et al, 2014).

A recent systematic review of research to develop a conceptual framework for personal recovery in mental health has nonetheless identified the key characteristics of recovery as being active, unique and individual. It also identified the central importance of connectedness; hope and optimism about the future; identity and overcoming stigma; meaning in life and empowerment (including focus on strengths) (Leamy et al 2011).

So how have mainstream mental health services responded to what is arguably the radical co-productive challenge of recovery, as originally conceived by service users and survivors? Another systematic review of research gives an indication of what has happened. Clair Le Boutillier and colleagues looked at set of twenty-two high quality research papers in order to find out staff understanding of 'recovery-oriented mental health practice.' **They identified three types of recovery:**

- **Clinical recovery** means that clinical tasks shaped what recovery is, with the defining power remaining with the psychiatrist and the definition often being 'relapse-free' with a focus on 'symptom remission.'
- **Personal recovery** was broadly in line with some of the original thinking on hope, autonomy and empowerment, partnership working with staff and citizenship involvement.
- **Service-defined recovery** was identified as 'a new conceptualisation which translates recovery into practice according to the goals and financial needs of the organisation… Organisational priorities influence staff understanding of recovery support. This influence is leading to the emergence of an additional meaning of recovery' (Le Boutillier et al, 2015 p.1)

According to the research by Le Boutillier and colleagues, the original meaning and power of recovery has reduced as it has been absorbed into and defined by clinical practice and mainstream, statutory mental health organisations.
Similarly, research by Mike Slade and colleagues has revealed that clinical interpretations of recovery mean that 'broader concepts of community and cultural resilience and well-being may be needed' (Slade et al, 2014 p.17).

It appears that the dominant powers within the mental health system - medicalised practice, organisational business and institutional administration – have a strong influence in defining what recovery is, rather than being transformed by it. However, Slade and colleagues note the importance of transformative co-production of mental health services to support personal recovery:

> **'shifting to practice that is built on equal partnership, hope-promoting and facilitating self-determination requires a transformation of services, practices and the paradigm within which they are delivered'**
> *(Slade et al, p.12).*

The evidence examined here on what has happened to personal recovery as it has been mainstreamed suggests Deegan's original recovery questions that demand working co-productively do not seem to have been widely understood or continuously reflected on.

Nonetheless, consistent with co-production's core values, it remains that citizenship, social justice and inclusion are fundamental for service users and survivors concerned with personal recovery:

'the recovery agenda for user-researchers blurs repeatedly matters about human rights and citizenship and so its policy implications extend beyond the notion of recovery alone, however broadly that has been defined' (Pilgrim & McCranie, 2013 p.38)

Mental health service user and survivor participation

The concept of service user and survivor participation has existed in mainstream mental health for at least two decades and was the result of campaigning by the mental health survivor and disability movements (Beresford & Carr, 2012). It has been the subject of research investigations by service users themselves as well as by non-user researchers.

At its most progressive, service user participation can be recognized as a form of co-production when it is characterised as:

- **'partnership'** with equal access to resources and decision-making power;
- **'delegated power',** where service users have dominant decision-making authority and opportunities for leadership; and
- **'citizen control'** where service users control organisations (such as user-led organisations) (adapted from Arnstein, 1969).

At its least progressive participation is tokenistic and only involves consultation on pre-determined decisions, where service users have no influence on defining what the problems are or the change that is required (Rose et al, 2003).

Those who get involved with designing, developing and governing mental health services consistently say they do so because they want to use their experiential knowledge and expertise to achieve change (Beresford & Carr, 2012). There is an expectation among mental health service users and survivors that their expertise will be regarded as an asset; that their experience will be respected as valuable knowledge; that decision making power will be equally shared; and that people with mental health problems can contribute to service transformation as citizens as well as 'service users' (Rose et al, 2003; NSUN, 2015).

However, in reality, mental health service users and survivors express dissatisfaction with participation in mainstream community and in-patient mental health services (Bee et al, 2015). In order to assess how ready mainstream mental health services are for the challenge of progressing transformative co-production, it is useful to look at some of the research on how service user participation in mental health services has worked to date. In 2003, a user-led study commissioned by the NHS reviewed literature on user and carer involvement in change management in mental health found that, in direct contrast to the power relocation demanded by transformative co-production,

> **'Strategies of user involvement can work to reinforce the power of professionals and managers. This is especially the case where the 'user card' is played strategically so as to bolster certain professional interests against other organisational interests' (Rose et al, 2003 p.12).**

'Strategies of user involvement can work to reinforce the power of professionals and managers. This is especially the case where the 'user card' is played strategically so as to bolster certain professional interests against other organisational interests' (Rose et al, 2003 p.12).

The researchers also found that organisational resistance was one of the biggest barriers to change resulting from mental health service user participation. A later user-led study of service user participation in mental health services examined the responses of managers and leaders in the NHS and social care (Rose et al, 2014). The researchers found that individual 'ordinary' service users could have relatively high levels of involvement in their local services and believed this had a positive impact. However, the picture was different for collective approaches as the researchers say that

'in studying user-led organisations, we found that they are working in a climate of change and complexity that has forced them to adapt and change, such that "traditional" styles of confrontation and campaigning have given way…this posed many challenges for the organisations we identified.'
(ibid p.xv)

The researchers also discovered 'similar issues of appropriate styles of behaviour and confrontation arose' for service user governors on NHS Mental Health Trust Boards. It appears from this study that similar things have been happening to mental health service user participation as with recovery. A radical approach becomes co-opted by mainstream services and becomes absorbed into organisational business, thereby losing its transformational co-productive power. Here, Rose et al's 2014 study clearly shows that the process of transformational co-production in mental health is being compromised by organisational resistance to the challenges posed by collective user-led organisations and by the demand to conform to corporate standards of expression, terminology and presentation in governance meetings.Further evidence of this organisational resistance to a co-productive process comes from another review of research into the barriers and facilitators to service user-led care planning (Bee et al, 2015). Bee and colleagues synthesized the findings from 117 studies, and concluded that

'service user involvement fails because the patients' frame of reference diverges from that of providers. Service users and carers attributed highest value to the relational aspects of care planning [but]…Service user-involved care planning is typically operationalized as a series of practice-based activities compliant with auditor standards' (ibid p.104)

This service-oriented procedural and managerial, rather than relational approach to mental health service user participation can often result in exclusion and disempowerment. Research shows it does not offer the conditions for a co-productive process, particularly where confrontation or challenge may precede collaboration as part of the process. The shortcomings of such participation strategies that disregard the assets and knowledge of service users and survivors are well documented in the research on user participation in mental health services and stand in opposition to the core values and building blocks of co-production, according to Cahn (2008). In her extensive research on mental health service user participation and democratic citizen forums, Marian Barnes (2002) identified particular issues for mental health activists and the expression of anger, emotion or the use of personal experiences and stories in official meetings:

'Consumers were expected to learn the rules of the game as defined by the professionals/bureaucrats and to play by them.' (Barnes, 2002, p.329)

Importantly for assessing the conditions for co-production in the light of the evidence on how organisations have responded to individual and collective forms of mental health service user participation, Barnes concluded that:

'If deliberative processes are not to reinforce existing exclusions then fundamental questions of exercise of power through control of the rules of the game of deliberation need to be addressed. These rules define both the way in which deliberation is conducted and who is considered to be legitimate participants in the process.' (ibid, p.329)

More evidence on rules, expression and exclusion can be found in the case study work of Suzanne Hodge (2005), who observed the dynamics of a forum where mental health service users and survivors were 'invited' into a dialogue with officials, in a 'service-led' initiative. She also found that certain topics such as electro-convulsive therapy (ECT) and the use of personal narrative or lived experience were not incorporated into the discussion, or otherwise 'translated' and steered by professionals. Hodge argues that this 'policing' of the discussion amounts to

'a significant exercise of power…in the context of an institutional setting… where the ability to exercise power in a meeting is linked to the institutional power relations in operation.' (Hodge, 2005, p.174)

Similarly, research on mental health service user participation by Lydia Lewis showed that power over the types discussion that could be had was maintained through 'the rules of the game, the rules of engagement and agenda-setting' (Lewis, 2014 p.1). The findings from these major pieces of research into UK mental health service user and survivor participation indicate that exclusionary strategies and disempowering dynamics can operate as part of organisational resistance to change. This suggests that there could be some fundamental challenges for progressing transformational co-production in mainstream mental health services. It is possible that existing participation initiatives in mainstream NHS mental health services may be relabeled as 'co-production' without any transformation of power and control.

Choice and control through direct payments

Mental health policy and research defined empowerment as having choice and control over support (Rose et al, 2014; HM Government 2007). It has also been argued that the individual level co-production of support plans, where the service user takes the lead and the focus is on their strengths, interests and ambitions, as well as their social and economic context and support needs, can be empowering for people with mental health problems. This also moves away from the traditional 'deficit' model (Coulson, 2007) where people are defined by what is 'wrong' with them and are assessed on what they cannot do, rather than what they can and want to do. One of the ways in which choice and control over care and support can potentially be achieved is through direct payments, so that the person can determine and purchase their own support, if they are eligible for social care funding.

Direct payments were pioneered by disabled people in the early 1980's who wanted to be able to have complete control of their own care budget so they could determine their own lives and live independently with the appropriate support. Direct payments were legislated for in England and Wales in 1997 (Glasby and Littlechild, 2009). The early research on direct payments for people with mental health problems provides another useful source of evidence for assessing

the readiness of mainstream mental health services to rise to the challenge of transformative co-production.

A study investigating the uptake of direct payments by mental health service users found that 'when given the opportunity, service users were able to use direct payments creatively to meet a range of needs in ways which increased their choice, control and independence' (Spandler & Vick, 2006, p.107). However, the study also found that organisational constraints and practitioner responses could restrict the extent to which direct payments could be empowering and support independent living.

The researchers concluded that one of the underlying issues lay with power relations between staff and service users, particularly for a potentially disruptive approach that gives control to service users and promotes their strengths:

'direct payments are part of a growing number of initiatives which de-centre the professional in terms of expertise and decision making, challenge the privilege of professional knowledge and promote more user-centred knowledge, definitions and alternatives. Such innovations necessitate professionals (and clients) being able to develop alternative modes of communication and practice to enable them to negotiate, and adapt to, the changing power relationships that such initiatives inevitably entail' (Spandler & Vick, 2005 p.154)

In 2005 a mental health project brought together service users and staff to discuss some of the difficulties with improving the uptake of direct payments in mental health. Participants were clear that some of the barriers existed in organisational culture and assumptions about risk and the capacity of people with mental health problems to manage. The cultural difficulties centred on 'prevailing views of mental ill health' that were primarily medical whereas direct payments imply a social response aimed to support the individual manage their mental health in ways different from traditional clinical options. Another unhelpful aspect of organisational culture was risk adversity and 'the preoccupation with risk was seen as incompatible with workers letting go of their control and supporting innovation in practice.' (Newbigging & Lowe, 2005, p.14).

Much of what was initially identified in research on direct payments in mental health surfaced again in later research on individual and personal budgets, namely that they can work well if administered properly when the right support is in place, but there are organisational and practitioner barriers to do with power, control and concepts of trust and risk (Webber et al, 2014; Carr, 2014; Carr, 2011; Glendinning et al, 2008).

Ten years after the original direct payments research, a study on power, choice and control in mental health personal budgets yielded similar and additional findings, particularly regarding perceptions of people's capacity and organisational culture:

'pressure on workloads and bureaucratized procedures could mean that some practitioners with tried to avoid offering service users the options of personal budgets or took over the decision making process because they did not have the time to establish a properly co-productive relationship' (Hamilton et al, 2015 p.18).

Notably, the research revealed that mental health service users' own perceptions of capacity impacted on the process and decision making:

'another major influence on how choice and control was exercised was how service users viewed their own capacity to make decisions and manage money – and how this was viewed by practitioners' (ibid, p.9)

In the discussion of the research findings, the authors analysed the effects of the wider institutional context on perceptions of power and agency on service users where they

'remained constructed in positions that still reflected their previous subjection within service discourses for that had told them that they could not and should not make decisions for themselves. This could then be compounded by current experiences that were shaped by practitioners who found ways of holding on to old forms of "power over", or by agency procedures that ensured that important decisions were made at a level where service users could exert little influence' (ibid, p.14).

Studies on direct payments in mental health show that there are particular organisational, conceptual and attitudinal difficulties for achieving choice and control for people with mental health problems. The policy of personal budgets was presented within a framework of co-productive service reform, but much research shows that the policy aspiration to relocate power and control to mental health service users is hard to achieve in reality (HM Government 2007).

Key themes
for mental health co-production

In this paper, research on empowerment, personal recovery, service user participation and direct payments has been used to assess how ready mainstream mental health services are for Cahn's original challenge of transformative co-production. Mainstream mental health services have found each of the concepts, developed and led by service users and survivors, difficult to define or implement, without co-option or dilution.

There are some notable and consistent themes arising from the overview of evidence on these radical ideas from service users and survivors and their subsequent mainstreaming in the mental health system, which are explored below.

Challenge and expression

'Righteous anger' and 'hell raising' have been identified as important to empowerment by and for people with mental health problems and for transformative co-production. Having the opportunity to communicate anger about mistreatment, harm or experiences of social injustice is both an integral part of mental health empowerment and of the co-production process.

Edgar Cahn is clear about the potential for challenge and confrontation to play a role in the co-production process.
Patricia Deegan describes the mental health and psychiatric system as one that demands obedience and compliance and that real change by and for service users and survivors will be uncomfortable. The capacity of practitioners to work in collaborative ways with service users and survivors may also be affected by this type of culture, particularly if they are expected to conform to rigid roles and administrative processes.

The evidence on what has been happening in mental health services shows that confrontation and the expression of 'righteous anger' as part of the process is often avoided, resisted or even pathologised.

Despite the fact that self-expression and self-determination are identified as factors for empowerment, they are not factors that appear to be present in mainstream mental health service user participation initiatives or service-defined approaches to promote choice and control. Emotional expression and the use of personal stories seem to be discouraged in participation forums that are run by mainstream mental health services. This is at odds with learning situations where students and practitioners engage with service user experiences and narratives to support professional development and reflective practice (Levin, 2004).

Challenge from service users and survivors is not always welcomed, neither sometimes is discussion about topics some practitioners and policy makers at those forums find uncomfortable, such as electo-convulsive therapy (ECT) or broader social issues like housing and benefits. Research shows that discussion and decisions are often service or practitioner led and that service users and survivors may find themselves having to conform to organisational or managerial norms and language to be heard or considered to be 'legitimate.' Because of this, service user and survivor organisations can find it difficult to continue their tradition of confrontation and campaigning, which is part of their broader social justice remit.

It appears that many mainstream mental health service participation initiatives continue to demand 'obedience' and conformity from users and survivors (and by extension, practitioners). Many attempts at participation and power sharing avoid confrontation, and can often result in forced consensus, disempowerment and ultimately, no change or transformation led by service users (Lewis, 2009; Rose et al, 2003). However, challenge and self-expression are vital for transformative co-production and empowerment in mental health, and often form an initial part of the process (Carr, 2007).

Institutional rules and resistance to change

Institutions and mainstream mental health organisations may demand conformity to norms of consensus-making and expression, which can make it difficult for service users and survivors to attain powerful positions of influence and to achieve change (Carr, 2007). The research examined here shows some of the different ways in which institutional power can be exercised, from requiring certain types of behaviour from individuals to absorbing and redefining transformative concepts such as personal recovery and direct payments in mental health.

One of the original challenges of personal recovery was to radically change mental health and social environments so people can grow, rather than be powerless and passive. However, research shows that, in mainstream mental health, recovery has become defined by services and oriented towards organisational needs and goals. This means there has been a shift away from a focus on personal hope and self-determination. Service users and survivors often see their recovery journey as taking place beyond services in society. However, there is now a restricted version of recovery in operation that is influenced by clinical understandings, organisational business and institutional administration, rather than by individuals, their experiences and lives.

Service user and survivor participation strategies and forums are often led by services that determine the rules and procedures and retain ultimate decision-making power. In some instances, mainstream services invite service users and survivors in on institutional terms and expect them to abide by their rules, even if those rules are not clear. Service user and survivor collectives that adopt a challenging approach and campaign on broader social justice issues can and often do find themselves side-lined by the very mental health services and organisations they are trying to change.

Direct payments in mental health can make a difference to people's lives if they are adequately funded and properly administered with the right support, but again, agency procedures can make it difficult for service users to take control and make choices.

Because of the organisational constraints on time and perceptions of capacity and risk, frontline staff and service users find it difficult to work together to plan support and staff find it challenging to let go of their decision making power and accept service user expertise of equal legitimacy to professional expertise. In some cases, service users have become so disempowered that they do not believe they have the agency and capacity to make decisions. Direct payments mean changing power relationships, but research shows that this has not widely happened because of the way institutional power works in mental health services and organisations.

The evidence suggests that mainstream mental health organisations retain institutional characteristics that can make them very resistant to change, particularly changes in power dynamics. Cahn's co-production core values and building blocks demand recognition of service user and survivor assets and their contributions, both to the services and support they use and to wider society.

As well as what they bring as unique individuals, service users and survivor have collective assets in the form of experiential knowledge about mental distress and mental health service use that they want to use to bring about the transformation of services and support and improve lives (Beresford, 2003).

The external acknowledgment and validation of assets and contributions is a requirement of co-production. However, the evidence shows that service user and survivor expert contributions to mental health services and support are not often validated or result in the fundamental changes to individual support plans, mainstream services or the provision of alternatives to psychiatry called for on the basis of experiential evidence.

Medical and professional role dominance

Cahn is clear that the framework for transformative co-production cannot be determined by what the service or professional wants, and yet approaches examined here that are potentially co-productive, are being determined by services and professionals.

Mainstream mental health services still operate on a 'deficit' understanding of mental 'illness' and have a highly medicalised, risk-averse culture that affects professional attitudes and practice in mental health. Practitioners who want to work in creative, co-productive ways can also find themselves restricted by their roles and the demands of the system. Research shows that a version of recovery has emerged that is being determined by clinicians and managers, rather than by the service users and survivors themselves. This appears to be affecting the way frontline practitioners can work co-productively with people who are experiencing mental health problems.

The evidence on mental health service user and survivor participation and on direct payments shows that their knowledge and assets are not being helpfully used, nor are they able to exercise decision-making power and influence. Professionals who are part of mainstream mental health organisations still feel an obligation to remain in control, partly because of concerns about risk, capacity and their duty of care (Carr, 2011). This also happens because of their obligations to organisational procedures and administration that, as research shows, prevents them from spending time developing trust and co-productive relationships. Service users say that they value the relational aspects of support for personal recovery, while professionals often work to what the organisational interpretation of what recovery is. This again diminishes the chances of co-productive working on an individual level.

In service-led participation initiatives, those with lived experience may find themselves competing to be heard with professionals who may 'translate', 'police' or even pathologises what they say and the ways in which they say it. Again, for progressing transformative co-production this is an issue about power and control of dominant clinical professional culture, as well as being about the recognition of assets and validating contributions.

Conventional means of involving mental health service users and survivors alongside professionals in decision-making forums can result in power inequalities and involve organisational resistance where voices and experiences are marginalised and decision-making agency is curtailed. Service user and survivor assets and expertise can be contested by professionals who are often constrained by their organisations, whereas transformational co-production means reciprocity, achieving equality and having mutual regard for relative expertise.

Service user and survivor collective activism

Community activism has been identified as a key factor in empowerment for people with mental health problems, and this is consistent with co-production's broader value base in social justice and investment in the social capital of communities.

Mental health service users and survivors have formed many activist collectives, user-led organisations, campaigns and collective peer support projects, which, in Cahn's terms, should be recognised as social contributions that can provide the platform for collectivism and challenge. Evidence shows that independent user-led organisations can provide forums

to discuss topics that are 'off limits' in conventional service-led or professionally-defined discussion spaces. Such knowledge generating activity should be recognised as important work and experiential knowledge as an asset to mental health services.

User-led organisations and independent collective peer support initiatives are seen as integral for recovery and direct payments, but their power to work in co-productive ways can be reduced when absorbed into mainstream activities and organisations. Research is showing that independent user-led organisations with an active campaigning or challenging approach are finding it increasingly hard to engage with service participation initiatives in mainstream mental health services. One of the reasons for this is the tendency of such initiatives and organisations to marginalize challenge and resist change. User-led organisations may then become reluctant to re-engage as they fear that their contribution will again result in no meaningful change (Carr, 2004).

Summing up:
Are conditions favourable for transformative co-production in mainstream NHS mental health services?

> '…to a much greater degree their plight was due to the systems and structures erected for dealing with madness, which turned people into rigidly dichotomized patients (aliens) and psychiatrists (alienists).' (Porter, 1987 p.231)

> '... power is an uneven and invisible resource, like oxygen. Often people only notice power when they don't have it. They are like people exiled to the mountain tops who gasp because they don't have enough oxygen, while the privileged people at sea level breathe so comfortably they never think about the supply of oxygen'. (O'Hagan, 2014, pp.217–218)

This overview of some of the literature about personal recovery, mental health service user participation, direct payments and user-defined empowerment has shown that there are several specific challenges for progressing transformative co-production in current mainstream NHS mental health services.

Regarding the evidence on personal recovery and direct payments there is a risk that co-production may be absorbed into and defined by mainstream mental health organisations and become part of institutionally or professionally defined procedure.

The research on personal recovery, service user and survivor participation and choice and control through direct payments shows that their potential progress transformative co-production can be seriously limited by institutional control. This is often through limitations on service users exercising their agency and power and through the maintenance of professional or service power and agency. Institutional control can also affect the way practitioners can work openly, equally and collaboratively with service users.

There are distinct challenges for co-production in mainstream NHS mental health services which relate to institutional

- resistance to change;
- restrictive administrative procedure and professional practice;
- avoidance of challenge, confrontation or emotional expression; and
- the demand to conform by institutional rules and cultural norms.

However, Edgar Cahn's original revolutionary idea of transformative co-production was about dismantling institutions, changing their cultures and practices and rebalancing power. His foundational view of co-production is about social justice and inclusion, with the fundamental conviction that there should be no 'throwaway people' because everyone has assets, strengths and contributions to make.

Transformative co-production is about disrupting traditional fixed roles and power relations between professionals and service users and should not be solely determined by the institution or organisation. Depending on the context transformational co-production may be collaborative, but it may also be confrontational. It may result in small but significant changes to individual

relationships between practitioners and service users, or it may mean larger service or system reforms. Radical change in mental health through transformative co-production can mean that 'hell-raising' and challenge can be a necessary part of the process.

Importantly, Cahn's universal core values are seen as a set of standards against which to test the 'integrity and authenticity' of the co-productive effort, and it appears that based on the evidence examined here, mainstream mental health services may find achieving that integrity and authenticity challenging.

However, if given facilitated space to meet and open up dialogue outside the system, mental health service users, survivors and practitioners could develop common values, aims and co-productive relationships:

> 'To build effective co-productive relationships it may be necessary, at least initially, to move away from the point of delivery and create forums in which officials and citizens can articulate service experiences, recognise common ground and negotiate service improvements' (Needham, 2008 p229)

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