Involving people with lived experience in strategic decision making ('Strategic Commissioning')

Discussion material

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IMPACT
Improving Adult Care Together

The Health Foundation

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How you can use this discussion material

Before our first session, we'd like everyone to read this document which summarises the evidence from research, practice and lived experience about involving people with lived experience in strategic decision making.

This material outlines the issue in terms of the challenges and potential benefits of including people with lived experience in commissioning, and explores some different ways to support people to do this.

The aim of this material is to spark discussions in your groups about your experiences and ideas for change. You will find a series of questions at the end of the document to support your reflection and the discussion with the others.

Summary

- This document is about **involving people with lived experience in strategic decision making in social care.**
- Evidence shows that involving people with lived experience during the creation, implementation and delivery of social care service is associated with better **tailored services** and **improved satisfaction** from the people using the services. It has also been shown that participation in the creation of the service has **positive effects on the wellbeing of people involved.**
- Using the **"ladder of participation"** the document discusses different ways to involve people with lived experience in decision making in social care**.** Following a review of these levels of participation, the document provides some **case studies of people with lived experience involvement in commissioning** - from engagement to co-production.
- However, the review also highlighted some of the **barriers to involving people with lived experience in the design, implementation and delivery of the service provision.** These include the lack of clarity in power distribution, small incentives for people to participate, reduced accountability between the public, private, and voluntary sectors, and burnout of users.

What's the issue?

The importance of involving people with lived experience in the development, implementation and delivery of health and social care services **in the UK has grown significantly in recent decades** (Ocloo et al., 2021; Hatton, 2017; Loeffler and Bovaird, 2019). For example, people with lived experience and their carers have now been active in the development and delivery of social work education since 2002 (Fox, 2022). Increasingly, service users are involved in social care and mental health research (Sankel and Sartor, 2022; NIHR, 2021). In the last few years, the involvement of people with lived experience has been also promoted in recruitment for the workforce – staff (Lovell et al., 2022).

Similarly, in the last 10-15 years there has been a **rising acknowledgement of the importance of including people with experiences of services in commissioning** (Loeffler and Bovaird, 2019) and **the management of social care services** (Hatton, 2017). These developments have been linked to a growing recognition of the **benefits** of involving the wider public contributing to research and care provision (Ocloo et al., 2021; Scie, 2022) as well as a growth in policy initiatives around citizenship, democracy and rights (Clarke et al., 2008; Loeffler and Bovaird, 2019). In particular, Hatton (2017) noted that recent developments to services in the UK incorporating **personalisation and 'choice and control'** have provided an important catalyst for moves towards empowering people in the adult social care sector. A further step in this process of empowering and involving people with lived experience in strategic decision making has been the Care Act 2014, which was one of the first pieces of UK legislation to include the concept of **co-production** in its statutory guidance (Scie, 2022a). One of the main features of co-production is the **power shift in the decision process** from being totally top-down to a **more negotiating and bottom-up process** (Bovaird, 2007).

Co-production has also been proposed as a potential **alternative to the present model for commissioning public services** (Boyle and Harris, 2009; Loefler and Bovaird, 2019). According to the discussion paper published by 'innovating public services', co-production can play an essential role in making our public services **more effective** because they can better meet the **needs of the community** (Boyle and Harris, 2009; Loefler and Bovaird, 2019).

A note about the language used in this document:

Various terms have been used to talk about the involvement of people in research, decision making and service delivery. Some of these are: clients, service users, experts by experience, beneficiaries, people with lived experience, community participation and so on. In England, the acronym PPI – for public and patient involvement, has also been used.

In this document we mainly use the term: **people with lived experience,** except when quoting other documents using other languages. The Oxford dictionary defines a **person with lived experience** as a person with a '*personal knowledge about the world gained through direct, first-hand involvement in everyday events rather than through representations constructed by other people*' (Chandler and Munday, 2016). This experience could be as broad as being a parent, or a youth, or more specific, such as having experienced loneliness, or having experienced discrimination (Woodal et al., 2019).

For the specific context of this document, lived experience also refers to **the experience of using a social care service,** which differs from the experience of those who might be designing or delivering that service (Ayiwe et al., 2022).

There are different strategies and levels of participation to include diverse people in the design, implementation and delivery of services (Bovaird, 2007; Ayiwe et al., 2022).

For example, Care Council Wales guideline (2017) distinguishes between **'commissioning for co-production'** and **'co-producing commissioning'**. In the former case, councils encourage providers to co-produce services, they are commissioning co-production. In the latter case, people with lived experience became an integral part of the commissioning process.

However, despite various good practices and increased attention to participation in policy documents, it has been noted that **often the involvement of people with lived experiences can be just a tokenist exercise**, rather than a real commitment to working together (Ayiwe et al., 2022; Beresford et al., 2023). The implementation of 'real' and meaningful involvement and co-production in strategic decision making is still limited and difficult to achieve (Burns et al., 2023; Scott et al., 2024; Beresford, 2019; Loeffler and Bovaird, 2019). A **series of barriers** and **bad practices** have been identified during the review, such as problems in power distribution, lack of training to facilitate equal participation during the meetings, and barriers to paying people with lived experience for their time. Bad practices in involving people with lived experiences can have a negative impact on trust and discourage future involvement (Ayiwe et al., 2022; Burns et al., 2023).

For these reasons, IMPACT has selected this subject as one of the topics that is going to be explored by the IMPACT Network delivery model.

What is the context across the four UK countries?

Across the four UK countries, there is a shared intention of involving people with lived experience in the commissioning process to provide services that are tailored to the needs of those who draw on care. The Care Act 2014 introduced the concept of co-production in social care across the four UK countries. However, the way how this is implemented is quite diverse across the UK on the basis of the governance framework and commissioning processes.

In England, chapter five of the white paper 'People at the Heart of Care' (2021) is about *'Empowering those who draw on care, unpaid carers and families'*. The white paper **acknowledges the importance of involving people in health and social care decision making.** Additionally, the Health and Care Act 2022 has determined important **changes in** the ways how **commissioning** is working on the local and national level. The act, in fact, invites **a more collaborative approach** which will also include the involvement of different parts (including local government, the voluntary, community and social enterprise (VCSE) sector, NHS organisations and others) to develop a health and care strategy for the area (Wenzel et al., 2021). However, **there is not a national guideline** of how to involve citizens in the creation of services. Each local authority is using a personalised approach to include people with lived experience in the commissioning process (Loeffler and Bovaird, 2019).

In Scotland, the **human rights framework and participation** makes the national context very welcoming to initiatives involving people with lived experience in the decision making process at any level (Scott etv al., 2024). The Scottish Government introduced legislation underpinned by co-production to integrate health and social care in 2016, and the National Care Service (NCS) is adopting a co-design approach to its development and it is also building capacity for co-production (Scott et al., 2024). However, **inconsistencies in the application of co-production** are visible across the country (Scott et al., 2024).

The Department of Health in **Northern Ireland** has put **co-production in health and social care** as one of the **main goals** since 2016. The following year, a review from the Department of Health NI called 'Power to People' reiterated the importance of a collaborative model based on service users' involvement (Burns et al., 2023). While health and social care have been fully integrated since the 1970s, government instability and disagreement on power sharing have resulted in limited policy changes (Scott et al., 2024).

In Wales, co-production is a core value of the Social Services and Wellbeing (Wales) Act 2014. The Act provides the legal framework for transforming social services in Wales and it provides not only a clear definition of what co-production means, but it has created a series of guidelines and a code of practice to allow the implementation of this shift across the whole of Wales. This also included an IMPACT study of the implementation of the act (Andrews et al., 2023).

Benefits of involving people with lived experience in decision making

Getting involved in decision making is not only a governance and policy makers' priority. Evidence shows that there is also a **real demand from people with lived experience to be included in the decision making process** (Ayiwe et al., 2022; Burns et al., 2023). During a workshop run by Alliance in Scotland, participants emphasised that often *'practitioners do not truly understand the experiences of people with lived experience'* (Ayiwe et al., 2022, p.18). For this reason, participants expressed the will to take part in all the steps of policy and decision-making. Participants highlighted that they don't want only being listened to but they want to be included in highlighting issues, formulating recommendations, and evaluating new changes (Ayiwe et al., 2022).

Evidence highlights a series of **benefits** that participation to decision making and the creation of public and social care services has on the individual, the services and, the wider community.

On the **individual level**, getting involved in decision making has been associated with:

- Feeling valued and empowered
- Improved confidence and a sense of purpose
- Ownership of the services
- Supporting outcomes like employability
- Improved social connections and peer support

- Better health and wellbeing
- Increased engagement and trust
- Higher levels of satisfaction with, and awareness of, services (Scie, 2022a; Woodall et al., 2019; Boyle and Harris, 2009).

Evidence shows that working alongside people with lived experience also benefits **services and practitioners**:

- Providing a better understanding of the needs of individuals
- Thinking differently about existing practices
- Developing a more authentic and human service
- Designing and implementing more tailored services
- Developing a more effective service provision (Woodall et al., 2019; Boyle and Harris, 2009; Loeffler and Bovaird, 2019).

Evidence also pointed out that encouraging people with lived experience to participate in decision making can have positive effects on **the wider community,** such as:

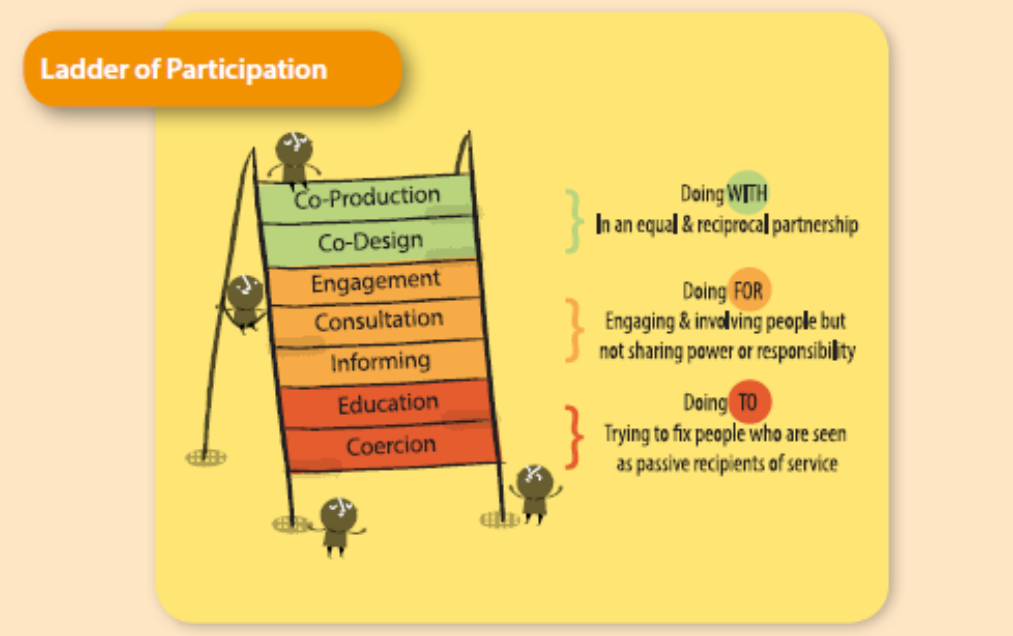
- Inclusiveness and diversity - giving voice to underrepresented groups of people with different knowledge and experiences of the same problem
- Better quality of life outcomes desired by both citizens and public service commissioners
- Supporting better use of scarce resources
- Sense of ownership of the final product - people are more likely to champion and promote the activity or resource within their local community, which may increase take-up, effectiveness, and sustainability
- Growing social networks to support resilience
- Community development and democratic participation (Loefler and Bovaird, 2019; Boyle and Harris, 2009; Beresford, 2019)

From engagement to co-production: How could people be involved?

There are **different ways to involve people with lived experience** in the decision making process and these require different levels of participation and empowerment (Ayiwe et al., 2022; Loefler and Bovaird, 2019; Bovaird, 2007).

In this document, we will use an adaptation of Arnstein's **'ladder of participation'** from the 2015 Public Health Wales guideline 'Seeing is Believing Catalogue of co-production case studies from Wales' (see Image 1), to explain the different levels to engage with people with lived experience in designing, planning, and delivering services.

Image 1: Taken from '*Seeing is believing: Co-production Case studies from Wales*'



On the **first two steps of the ladder** are **coercion and education:** at this level, the people are seen as passive recipients of service (Doing to).

In the **middle of the ladder,** we find more positive actions such as **informing, consultation and engagement**: at this level people are involved but there is no sharing of power (Doing for).

On the **highest levels of the ladder,** we find **co-design and co-production**, which aims to equal the distribution of power and participation (Doing with).

In this adaptation of the ladder, **co-production** is the highest level of participation. However, it is worth mentioning that in the original version the highest level of engagement corresponds to **complete citizen power.** Table 1 explains this next step in a more clear way showing that whilst co-production has as a core value the equal sharing of power and responsibility, **self-organised community provision** is planned and delivered by the people in the community.

Table 1: Taken from *'Seeing is believing: Co-production Case studies from Wales'*

PLANNING BY / DELIVERY BY	PROFESSIONALS	PROFESSIONALS & COMMUNITIES IN PARTNERSHIP	COMMUNITIES or CITIZENS
PROFESSIONALS	TRADITIONAL PROVISION professional services	CO-DESIGNED but professionally delivered	
PROFESSIONALS & COMMUNITIES IN PARTNERSHIP	CO-DELIVERED but professionally designed	CO-PRODUCED shared responsibility: citizens, communities, professionals	
COMMUNITIES or CITIZENS	CO-OPTED community delivery of professionally-planned services		SELF-ORGANISED citizen activists and/or community provision

According to table 1, **traditional provision** doesn't leave space for people with lived experience contribution. **Co-designed and co-delivered services** imply community participation. However, the final service is designed or delivered by professionals who maintain the power over it (Beresford, 2019). **Co-production,** by contrast, allows the equal collaboration and shared power in design and delivery responsibilities over the service planning and delivery (Brandsen and Honingh, 2015). The highest level of participation is given by **self-organised community provision**, where services are planned, delivered and under the complete control of the citizens (Edelembos et al., 2018).

Involving people with lived experience in 'strategic commissioning'

The concept of commissioning was introduced in the UK in the 1990s but it has evolved since then (Wenzel et al., 2022). As discussed in the previous section, there are some differences on how commissioning works across the four UK countries (Scott et al., 2024). However, for the purpose of this document we will use the Scie (2022b) definition:

"Commissioning [...] represents a systematic approach to planning and resourcing public services. The aim of all social care commissioning activity by local authorities is to achieve the best possible outcomes for the community as a whole and for individuals who require care and support. So it's about promoting better lives".

Commissioning is a cycle which includes the following activities:

- Identifying and Assessing needs
- Setting priorities
- Planning services

- Procuring services
- Monitoring quality

These activities are linked and they should inform each other in a circular way (Wenzel et al., 2022). **'Strategic commissioning'** should be focused on outcomes, such as wellbeing and health, rather than services (Loeffler and Bovaird, 2023). 'Commissioning for Better Outcomes' (2015) identified four main domains to good commissioning:

- Person-centred and outcomes-focused
- Inclusive
- Well led
- Promote a diverse and sustainable market

Thus, good commissioning should **put the needs of citizens at the centre of the commissioning cycle** (Wenzel et al., 2022; Loeffler and Bovaird, 2023). However, in a review about co-produced commissioning in the UK, Loeffler and Bovaird (2023, p. 241) found that *'most commissioning practices have not put much weight on the involvement of service users and local communities in the commissioning cycle and have been relatively weak in assessing and improving outcomes'.*

In order to have a complete co-produced commissioning process, which is the highest level of the Arnstein's **'ladder of participation'** (see Image 1), citizens should be involved at any stage of the process from assessing needs to monitoring quality (Loeffler and Bovaird, 2023).

Case studies

In the three boxes below, we have selected four **different ways to involve people with lived experience in decision making.** Each case study starts with a brief description of the method to involve the person and it discusses it in relation to the 'ladder of participation'.

It is worth mentioning that for the purpose of this document, we have excluded **informing people.** This form of 'participation' relies only on providing information to people with lived experience about policies or services. Therefore, it excludes any opportunity for further involvement.

CASE STUDY 1: CONSULTATIONS and STEERING GROUPS

Consulting people with lived experience asking for their opinions and feedback about services, policies, and laws **is a way to involve people during the decision process.**

There are different examples of how this modality has been applied across the four UK countries:

- The Scottish Government invited people with lived experience to participate in an online consultation for the approval of the new Learning Disabilities, Autism and Neurodiversity Bill (LDAN) in 2024.

- The Northern Ireland Department of Health's consultation on The Reform Of Adult Social Care in 2022.
- Mental Health and Wellbeing Plan Consultation – England 2022.

Consultation is appropriate when you can offer people some choices on what you are going to do - but not the opportunity to develop their own ideas or participate in putting plans into action (Partnership.org.uk). Information can be gathered through surveys, focus groups and interviews.

In the **'participation ladder'** (Image 1), consultation is labelled as a **'doing for'** type of activity because people don't share responsibilities or power. Thus, consultations do not require any obligation for decision makers to feedback, follow up, or act on this (Ayiwe et al., 2022) and for this reason, there is always the risk that they are used as a tokenistic thickening exercise (Beresford, 2019). **Tokenism** happens when engagement is carried out for performative reasons, without meaningful intention to listen to or act on the input of people with lived experience (Ayiwe et al., 2022) (see section on the barriers to involvement).

People with lived experience can also be **involved in steering groups**. While consultations are time limited, steering groups can have a variable time. These groups bring together people with specialist skills and expertise to a project including people with lived experience. The **level of engagement expected is higher than a consultation** because it requires more effort and responsibility from participants. Groups like this are invaluable to making sure the voice of lived experience remains at the core of our work and decision making (Mind, 2024). Some examples are:

- Carers Steering Group in Powys (Wales)
- Open Government Partnership Steering Group (Scotland)
- Carers Steering Group in Reading (England)
- Steering Group - All Ireland social prescribing network (Ireland)

In **strategic commissioning**, steering groups can be created to support the process of commissioning during the analysis, planning, creation of services, and reviewing the impact of the services. Looking at **Table 1**, a steering group requires a certain level of responsibility but again **the level of power in the delivery** of the change is limited.

CASE STUDY 2 - COMMISSIONING INDEPENDENT ADVOCACY

Strategic commissioning and the Care Act 2014 expect local authorities (health and social care Trust in Northern Ireland) to involve people in decisions about their care and support. **Commissioning an independent advocate,** where the person has substantial difficulty being involved and has no appropriate individual to support them, has been a solution adopted by some councils **to support people with lived experience in getting involved in these decisions.**

According to Scie (2022b), commissioning integrated advocacy can offer benefits including:

- Easier access to multi-skilled advocates
- Improved working relationships
- Better communication

The **main role of advocacy** is to support people to say what they want, securing their rights, representing their interests and obtaining services they need.

Whilst independent advocacy can promote people with lived experience's involvement in decision making, it is the way this method is implemented in the commissioning process that allows a shift from the middle **levels of the ladder of participation (Doing for)** to the **higher level (Doing with).**

Scie (2022b) guideline highlights the **advocacy under the Care Act should be commissioned in meaningful partnership with people with lived experience.** Whilst the care act doesn't directly mention advocacy, Scie (2022b) however, suggests that good practice in commissioning advocacy includes:

- working with advocacy providers to develop solutions and overcome barriers
- working with people who use services, carers and the local community to understand what is important to them
- incentivising providers to work together and with local communities recognising that partnerships take time and investment
- realising the potential of market shaping and its role in building the capacity of user-led and community organisations to deliver advocacy under the Care Act
- sustaining provision by agreeing three-year contracts as a minimum and including flexibility to respond to changes in demand

If you are interested to know more about commissioning independent advocacy, these three case studies show where this has been implemented:

- Manchester
- Essex
- Suffolk

CASE STUDY 3 - CO-PRODUCTION in COMMISSIONING

"Co-production is not just a word, it's not just a concept, it is a meeting of minds coming together to find a shared solution. In practice, it involves people who use services coming together to find a shared solution. In practice it involves people who use

services being consulted, included and working together from the start to the end of any project that affects them." (Ramsden, 2010, p. 7)

As seen in the **ladder of participation**, co-production in commissioning means the equal distribution of power and responsibility between people with lived experience, those who deliver the services and those who commission them. There are two main ways in which commissioning can really involve co-production in public services:

Commissioning co-production.

When councils encourage providers to co-produce services, they are commissioning co-production. Making sure that local providers design and deliver services in a co-produced way is an important step, and something that should be encouraged. However, this is limited to how people with lived experience can shape commissioning.

Co-producing commissioning.

Co-producing commissioning means equally involving people who use services, carers, families and communities throughout the commissioning cycle. Here, people will help to:

- Explain about local needs, aspirations and assets
- Make important decisions about what things are needed to make sure people have better lives and how to make these things happen
- Decide which providers are chosen to provide services and support
- Check and feedback about how well providers are doing and how they could do better (TLAP, no year)

Loeffler and Bovaird (2019) defines this as co-commissioning - this requires going beyond traditional consultation (case study 1). Co-commissioning expects the voice of citizens being embedded in any stage, at any stage of the commissioning process, but it is also expected to have a certain degree of responsibility for service delivery.

As explained by Loeffler and Bovaird (2019, p.242) *"co-production is not just an 'add-on' to some 'nice-to-have' discretionary services, on top of the statutory core services offered by public service organisations. On the contrary, citizen contributions are often a 'must have' to reduce the demand on both statutory and discretionary public services."*

This implies that people with lived experience should be included in all the four key areas:

1. **Identify and Analyse:** understand the needs that must be addressed, the values and purpose of the agencies involved, and the environment in which they operate
2. **Plan:** identify the gaps between what is needed and what is available, and decide how these gaps will be addressed
3. **Do:** secure services and ensure they are delivered as planned
4. **Review:** monitor the impact of services and approaches and ensure any future commissioning activities take the findings of this review into account (Scie, 2022b)

The review identified a series of elements for good co-production:

- ***Long-term relationships,*** *where all parties make substantial resource contributions* (Bovaird, 2007)
- Clarity of **goal**
- **Remuneration** for service users engaged in co-production is recommended
- A procedural and ethical framework for co-production practices should be put in place

Few examples of co-commissioning has been implemented:

- **Nottinghamshire County Council**
- **Doncaster Council**

Both these examples have integrated their 'local account' into this work, Doncaster took this through local political processes, whilst Nottinghamshire are working on a co-produced plan for making this happen, called 'Better Together'.

Bad practices and barriers to involve people in decision making

So far, the document has focused only on the benefits of involving people with lived experience in decision making and described some good practices with different levels of participation. In this last section of the document, we will discuss what the evidence says about the **barriers and the effects of bad practices when attempting public participation.**

Although the benefits of participation have been acknowledged, and there is a willingness to integrate co-production in the commissioning process, it is important to note that **meaningful involvement is not easy to reach.** A report produced by ALLIANCE (2022) has identified some of the main barriers to meaningful involvement of people with lived experience in decision making:

- Lack of training of the decision makers to communicate and understand the needs and problems of people with lived experiences
- Power dynamics (e.g. between commissioners and third sector, and between people with lived experience and those providing services)
- Limitation to participation (e.g. pay for contributions)
- Meaningful co-production is a challenge in the current practice environment because the bureaucracy of the present system doesn't allow clear and consistent communication between people using services and professionals (Aywe et al., 2022)

As we have seen in **Case Study 1 - Consultation** this can be a way to involve people in decision making. However, there is the risk of transforming this into a token, especially if the consultation is limited to few people with lived experience in the community. Additionally, if

people feel like they haven't been heard, there is no follow-up about what people shared, and participants to the consultation have no control over what is done with their experiences, this can be discouraging for participants (Ayiwe et al., 2022).

When the aim is to reach **co-production** (Case study 3), this requires a commitment to a complete transformation in the way decisions are made at all levels of the commissioning process. Some of the **main barriers to co-production** identified during the review were:

- Systemic and political barriers (e.g. timing for decision making, limited resources)
- Tokenistic involvement of people with lived experience
- Not enough information about opportunities to participate/information about participation not reaching the target population
- Practical barriers/lack of inclusive spaces
- Lack of language and cultural sensitivities
- Reliance on organisations for participants
- Difficulty of routinely delivering in a truly co-productive manner given the context and structures in which they operate
- Conflicts resulting from differences in the values of the co-producers
- Incompatible incentives to different co-producers
- Unclear divisions of roles, free-riders
- Burnout of users or community members
- Undermining of capacity of the third sector to lobby for change (Ayiwe et al., 2022; Bovaird, 2007)

Some authors pointed out that whilst **co-production** is often seen as the 'gold standard' of public involvement, there are concerns in increasing its implementation. For example, Bovaird (2009) points out that co-production with its focus on equal contribution and power could **blur the boundaries between the public, private, and voluntary sectors.** The risk of this shift in power distribution could lead to **a reduced accountability from the public sector** towards the quality of the services provided.

Others, by contrast, claimed that **co-production might come at the expense of service users and community-led approaches** (Scott et al., 2024; Beresford, 2019). Beresford (2019) noted, in fact, that while guidelines to co-production could favour the involvement of people with lived experience in decision making, these tend to make this change too simplistic. He also adds that the only essential step to achieve real public participation is a wider transformation aimed to 'develop modern democracy more generally'.

Having read the material above, in the first Local Network Meeting, we'd like you to discuss:

Your experiences…

- Would anyone like to share their experiences of 'being involved as/involving people with lived experience in strategic decision making'?
- What helps or makes it difficult to involve people with lived experience in strategic decision making?

Thinking about this discussion document…

- Does anyone in the group have experience of any of the models described in the discussion material? Or is aware of other good practices/models that involve people with lived experience in decision making?
- Were there any ideas in this document that you think could facilitate people with lived experience to get involved in strategic decision making?
- Anything in the document you didn't agree with, or didn't match your experience?

Next steps…

- Are there any next steps you'd like to agree as a group? Anything you'd like to discuss?
- Do you think there is anyone else who should be involved in your meeting?
- Is there anything you need from the IMPACT team?

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