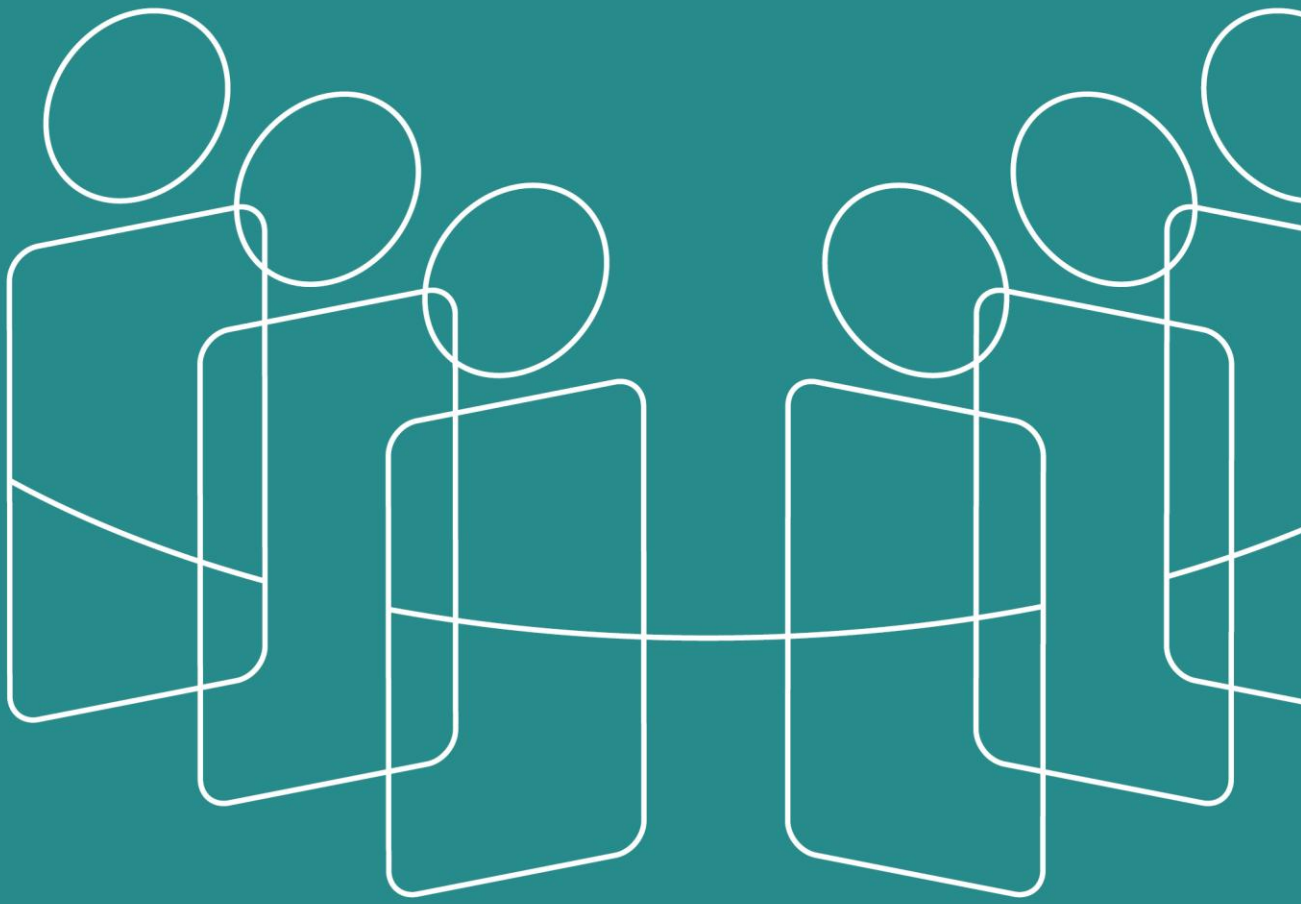
Inclusivity and Co-production

A trauma-informed guide for Fife



Lived Experience Team
GROWTH THROUGH PARTNERSHIP

families in trauma and recovery

NHS Education for Scotland

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Fife Council

Fife Health & Social Care Partnership

NHS Fife

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A fife co-production by:

- fife voluntary action's lived experience team,
- families in trauma and recovery, and
- the transforming psychological trauma implementation co-ordinator

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Introduction

Co-production has many definitions and what we describe here highlights the report author's perspective on what co-production is. Co-production helps to ground services in reality (NHS England). It is "A way of working whereby citizens and decision makers, or people who use services, family carers and service providers work together to create a decision or service which works for them all. The approach is value driven and built on the principle that those who use a service are best placed to help design it" (National Occupational Standards).

In essence, co-production is the process by which the people using a service are "included and become involved in the planning, development and delivery of that service to make improvements' (Clinks, 2011). Through co-production those with expertise by experience, by profession or by leadership can make "better use of each other's assets, resources and contributions to achieve better outcomes and/or improved efficiency" (Clinks, 2011, pg3).

When we talk about inclusivity and co-production, we are going beyond people with lived experience sharing their stories with professionals, beyond advisory panels. Instead we work from a place where the power held by experts by profession and experts by leadership is shared with those with lived experience in an effort to co-design and produce resources, services or some defined outcome to aid services to function more effectively. People with lived experience bring the experience of their whole journey to influence and shape services. The starting point for co-production should be before any decisions have been made on what the outcome should be.

Within the report we have referred to and highlighted a range of the available resources that describe and reflect on co-production. This is thankfully an area where there is significant interest at present, driven by a range of factors. It is perhaps likely that this document will be superceded by further work, including the Authentic Voice project (by Resilience Learning Partnership, SafeLives and NHS Education Scotland) and From Struggle to Strength (Fife Voluntary Action).

In particular the Social Care institute for Excellence resource is a useful guide to co-production - Co-production in social care: What it is and how to do it - What is co-production - Defining co-production (scie.org.uk)

But just because more guidance is coming, that is no reason not to start now. We would recommend that if you are interested in co-production the time to start is now. Meaningful co-production takes time.

The way to start is by having a conversation. For experts by profession this is perhaps easier, and in effect due to the way services are currently set up, the initial spark for change may need to come from within established services and from experts by profession or leadership. If you are from one of these groups and are reading this document, the best way to get started is to reach out to lived experience groups specific to your area of work. An initial conversation to get to know those involved and to talk through some of your ideas can be a valuable starting point in thinking about co-production.

We thought about how the initial ideas of co-production can start. For it to be co-production, individuals with lived experience should be included, involved and valued through all parts of the development of the project. The statutory organisation should arrive with ideas rather than plans and should be open to the ideas of the lived experience members of the co-production team.

Though the writers' focus was on thinking about co-production to help services become trauma informed, we hope that this guide can be helpful more widely in any area where a co-production approach is being considered.

Background to the project

Members of FVA's Lived Experience Team [1] and Fife Transforming Psychological Trauma Implementation Co-ordinator met in August 2021 (virtually) to discuss doing something together. The Lived Experience Team had lots of understanding of service user involvement and co-production projects.

We decided to look at what Co-production might mean, to develop a guide for enacting co-production in a safe trauma informed way that would be meaningful and sustainable.

Developing this document became a piece of co-production in itself and the lessons learned along the way inform the project. As part of our Project, we asked local organizations and people with lived experience for their views on co-production through an online survey. We thank them all for their responses which are embedded within the report. Our survey on experiences of co-production was sent to a group of local individuals and third sector organizations whom had an interest in co-production. We received 9 responses.

[1] Including the CEO of Families in Trauma and Recovery (FiTaR)

Why co-production is important

While the breadth of initiatives that can be considered as part of co-production means there will always be differences in how it is delivered between projects, these principles from the New Economics Foundation (2012) are helpful to consider. Co-production initiatives:

- define people who use services as skillful and knowledgeable resources
- break down the barriers between people who use services and professionals
- build on people's existing capabilities
- include reciprocity (where people get something back for having done something for others) and mutuality (people working together to achieve their shared interests)
- work with peer and personal support networks alongside professional networks
- facilitate services by helping organisations to become agents for change rather than just being service providers.

Central to co-production is a shift in the balance of power which facilitates the voices of those with lived experience to be heard as equal partners. It should be an empowering process, giving back control to people who may have had experiences of no control or of being controlled.

Our survey responses highlighted that co-production provides to those with lived experience more control and power over what services are provided and how they are delivered. They valued that co-production was a collaborative effort and recognized the value of lived experience of trauma survivors. Co-production is thus a means of creating partnerships and putting those with lived experience at key decision making points. It is a method to focus on strengths and partnership. The respondents were hopeful that co-production produced more effective services and a commitment to co-production signals a commitment to meaningful engagement and collaboration.

Drivers for co-production

Survey respondents highlighted that their motivation for engaging in co-production, both as individuals and as organizations in collaboration with statutory bodies, was to provide the best experience for those who access services. In particular, respondents linked co-production to trauma informed care.

Lived experience and third sector organizations can bring flexibility, innovation, and a different perspective. It is an approach to challenge systems and ensure the voice of those who access services is heard and acted on. Survey respondents highlighted that co-production was a means to move towards trauma informed care and a way to reach those in need more effectively.

There is widespread support for the importance of co-production in developing services, The Scottish Approach to Service Design is a Scottish Government policy driver for co-production, with an aspiration that *"the people of Scotland are supported and empowered to actively participate in the definition, design and delivery of their public services (from policy making to live service improvement)"*. No One Left Behind considers the role of service user voice in the commissioning, design and continuous improvement of employability services. Healthcare Improvement Scotland highlight the role of co-production and "*ensuring consistent and meaningful engagement of people in the design and delivery of their care"*. The strategy for Mental health and wellbeing in primary care services highlights the importance of *"local engagement and communication, including securing lived experience to inform local planning"*.

Involving people with lived experience in the design and evaluation of services and systems is a key driver of trauma informed service change. Services should work with the people that access the service. It can ensure that the services that are provided best match the needs of those accessing them. From a trauma informed approach involving people with lived experience of trauma in how a service is designed and delivered helps services recognise where people are affected by trauma and adversity and helps develop systems capable of responding in ways which **break the cycle**; support **recovery**; **address inequalities** and **improve life chances**. (NES, 2019)

Survey respondents had clear ideas about how working with local Councils and Health Boards could boost the offerings of their organizations, particularly collaboration with mental health services. The respondents were tentatively hopeful about a move towards co-production but highlighted that this needed to be embedded in the culture and leadership of the organization and be underpinned by a willingness to commit to the timescales and the different way of working that comes with co-production. Respondents highlighted the authenticity of materials produced through co-production and the positive experience of engaging in this type of work.

There was a recognition that current service user involvement was often around consultations or people with lived experience sharing testimonials rather than true co-production. There was wariness that this type of involvement is being badged as co-production.

What gets in the way of co-production

Through our discussion and survey results, we identified a number of barriers to co-production. We think it's important to lay these out here to look at how we can overcome them.

Safety

Safety is a core principle of trauma informed practice. All people involved in co-production should be able to feel physically and psychologically safe. All participants should experience the co-production experience and the interpersonal interactions taking place within the setting as safe, inviting, and not a risk to their physical or psychological safety.

There are barriers to safety from the perspectives of both experts by experience and experts by profession. One particular barrier is that people with lived experience might not want to enter a clinical environment or work with those (or colleagues of) people who they have had previous negative treatment experiences with. Thus, for experts by experience there may be negative or traumatic experiences of services meaning that those with lots to offer don't come forward or involve themselves with those services. To reach "the quiet voices", thought must be given to the setting and those involved in the co-production so that people feel comfortable to come forward. Experts by profession should be sensitive to the impacts of trauma and have the interpersonal skills to connect and make working relationships within the project. Commitment, openness, being comfortable in a team environment, and a facilitative approach can be key qualities needed to ensure safety in co-production. Potentially, consideration should be given to adopting a named facilitator who can ensure all voices are heard and thereby aid collaboration.

For the experts by profession, challenges to safety can come from a sense of clinical responsibility within the co-production group. This should be considered at an early stage in collaboration with the lived experience members of the panel. Though every effort should be made to resist re-traumatisation there may be instances where having a dedicated contact external to the co-production to provide wellbeing support can be a helpful means to reduce any sense of responsibility held by professionals.

Threat

Our discussions highlighted a sense that threat was a barrier to investing time in co-production. We recognize the strain felt across health and social care systems and that this can leave little space for contemplating change and a difficulty for the system to hear frank feedback or advice on how to "do better" without feeling threatened or attacked. This barrier is important to acknowledge in that experts by profession or experts by leadership also have needs. Handing over power and working alongside those that use our services can be challenging in this context of service pressure, low staffing numbers and high levels of health and social care worker stress. Staff wellbeing and readiness should be considered in advance of committing to co-production. However, this should not be a reason to engage in service developments in a way that excludes lived experience.

Tokenism

There is a risk of tokenism in lived experience involvement. This is illustrated in the Value of Lived Experience Report (Sandhu, 2017):

- Patient involvement is designed in a way that avoids criticism or change and to give the appearance of involving communities
- Involvement processes are used as "tick the box" exercises
- The sense of lived experience involvement as "tokenistic" becomes a feedback loop where these efforts are not fully pursued or avoided as they are seen as unhelpful or too "messy"

Tokenism becomes more likely the further you move from co-production as a goal. Maintaining control over what is open for discussion can lead to an imposition by experts by knowledge or leadership leading to sessions that become about feedback. If this happens, "involvement" can become experts by experience members providing feedback and then the experts by profession or leadership deciding to "take it or leave it".

Again Sandhu (2017) highlights that this can look like:

- Asking for feedback on decisions that are already made
- Seeking feedback from those aligned to the organization or who are perceived to "toe the line"
- Involvement late in the process (providing a stamp of approval)

Overcoming tokenism (and fears of tokenism) rely on the trauma informed principles of empowerment, trust and collaboration. Openness from the experts by profession on what is possible and what is not possible as well as openness on what they are bringing to the co-production effort (acknowledging that we all at some level think our own ideas are the best ones). This barrier is best overcome by demonstrating true commitment to co-production in one's actions.

Power and how it operates

Power can become a barrier when it is not acknowledged or addressed. This can be overcome in co-production by building trust and recognising power.

We can recognise the power differential through recognising that professionals hold a lot of power, while people with lived experience often have had experiences of powerlessness and may remain fearful about being in care of services again.

Survey respondents highlighted the importance of handing over the "control" to the participants. This requires the patience to allow the process to evolve naturally (see Time to Form below). Shared decision making is at the core of co-production, it should begin at an early stage and include making decisions on funding.

There is also a requirement for relationships and a social element to the process. It is important to start a co-production effort by meeting as people rather than as job titles. Balancing tasks such as chairing, minute taking, making tea/coffee, can work to reduce traditional hierarchies. Inviting everyone to be vulnerable and share something personal (e.g. the dreaded icebreaker process) to allow us all to see each other as people rather than job titles.

Reducing the impact of power may also be about reductions in formality. Consider where meetings take place (also a consideration for safety) and acknowledge where there are possible symbols of power (institutional signifiers or backgrounds on Teams/Zoom). When we are comfortable in a setting, we are more likely to be able to collaborate effectively. We may need to proactively create an atmosphere (even if it is virtual) that fosters co-production.

However, it's also important to recognise how power can be used to benefit co-production, for example recognising that you have access to funding, resources or other things that will drive the project forward.

Time to form

We recognized that launching directly into a co-production task can be difficult particularly when people come from diverse backgrounds and experiences and have different expectations. Time to come together as a group is time spent fostering an atmosphere. We need to take time to nurture an environment and learn how you communicate as a group.

In particular, when most contact is online, having an early opportunity to meet in person can build a sense of a team or group that are working together. Having an open discussion around timescales and commitments for the co-production is important even if these are initially guestimates! Part of valuing everyone equally is about valuing their time and commitment, ensuring that you provide timescales that avoid undue pressure to complete tasks and consequently crush creativity.

What values are important?

When thinking about what qualities we need within people involved in co-production, across the three types of experts we identified some key qualities needed to engage in co-production:

- **Willingness** – understanding it won't be perfect, that people are people and can make mistakes. Being willing to learn through the process.
- **Curiosity** – Being curious about the experiences of others within the co-production. What is it like to access the service? What is it like to work in this service?
- **Openness and Humility** – Being able to hear different points of view, different perspectives and being able to meet these ideas with openness and acceptance. We might come in with clear ideas, but part of co-production is about molding something together rather than recognising one person's dogmatic view of what "should" happen.
- **Trust and Integrity** – Trust within services about the outcome, that it will be acted on and changes will come out of it. Trust within the co-production that everyone's contributions will be met with respect.
- **Honesty** – Being clear and upfront about any issues that arise, being honest about your own aims within the co-production.
- **Humour** – Being able to build cohesion through humour, to project authenticity and being able to connect in different ways

Experiences of co-production

Survey respondents had positive experiences of co-production. They highlighted that accessing funding around co-production was a very competitive area and were saddened that the system of funding leads to this competition rather than collaboration.

Survey respondents from organizations highlighted ways that they had engaged experts by experience including involvement in recruitment, in developing training, in participatory budgeting and in steering groups for service change. Survey participants also highlighted positive experiences of service user involvement activities where they recognized genuine collaboration. Survey respondents highlighted the importance of thinking about different ways to share resources and recognizing how valuable collaboration can be to third sector organizations.

We also identified the importance of recognition of the contributions of those with lived experience. Ensure that those that contribute to co-production or other initiatives are recognized (such as in the authorship of reports or acknowledgment on materials produced) is a tangible expression of valuing contributions.

This feedback highlights the breadth of experience of co-production within Fife that will help overcome some of the barriers we have identified above.

Payment

We would direct to and recommend the Scottish Human Rights Commission report on paid participation.

Survey respondents highlighted the need to negotiate and openly discuss payment for involvement and the extent of this. Payments in kind, vouchers, reciprocal training, access to buildings for use by organizations were suggested. It was also acknowledged that some people with lived experience would not expect or seek payment as they get involved in these roles to "give back". At a minimum, travel and/or digital costs should be reimbursed but this area should be openly discussed within co-production.

Organisations or groups that have developed groups of people with lived experience which then contribute to co-production could be rewarded/supported in a range of ways including financially, or by means of resources.

Formal acknowledgment of all contributions, for example as authors of co-production reports is important. This can involve naming groups of individuals (for example FVA's Lived Experience Team, and Families in Trauma and Recovery in this report).

We would suggest that those with lived experience are valued within co-production and that an open discussion about how their time commitment will be recognized is an early part of the process. Considerations of lived experience involvement should be budgeted for and the extent of time should include time for preparing for meetings rather than being solely limited to direct meeting.

What could statutory organisations do to foster co-production?

Dedicate resources

As highlighted by the Authentic Voice Discovery report there is a need for dedicated resources within systems for lived experience work. This may be through having named points of contact that can facilitate and make connections between services and experts by experience. This will also include budgeting for co-production, including having mechanisms for fair payment of those involved in co-production.

Listening to ideas and responding

We thought about how co-production can be one-way at the starting point, with the voice of lived experience being invited in. Health and Social Care and Local Authorities should have a way that third sector organizations or lived experience groups can approach services for support with their ideas. We thought about how services can respond helpfully with advice, even when saying no to direct involvement.

Lived experience organisations should be empowered and have a route to co-producing services with statutory organizations. There have been huge developments in service user involvement in applications for government or grant funding, but there is yet no means for these organisations to link up with Fife Council, Fife Health and Social Care Partnership or NHS Fife.

A supportive culture

In line with ideas to embed co-production in leadership, ensuring lived experience representation on Boards and Strategic groups was highlighted by survey respondents as a way to foster a culture of co-production.

Survey respondents highlighted that the culture should be open to try new pilots and initiatives with the acceptance that these ideas will not always work but are always an opportunity for learning.

A key point was ensuring that co-production is introduced before service developments start. This was seen as the separating factor between co-production and consultation and was seen as involvement at all stages rather than being invited to comment at a late stage in the process.

Advertising widely was seen as a way to widen involvement. A conference or online forum promoting co-production was also highlighted as a means to build a culture of co-production across services and bring together those across services who are passionate about co-production.

As an example of this approach in action, for the No One Left Behind project, Fife Voluntary Action worked with Fife Centre for Equalities and undertook direct outreach to groups who are often otherwise 'easy to ignore' such as those from ethnic minority backgrounds or people from LGBTQ+ communities.

Contact us

Fife Voluntary Action's Lived Experience Team can support and enhance your research, policy work, service design and staff training!

Our tagline is 'Growth through Partnership' because we believe that when we work together, bringing the insight of lived experience with the knowledge of professionals, then everyone gains.

If you are interested in drawing on the experiences and expertise of members of the LET to help you achieve your objectives, please contact pam@fva.org

For any other inquiries for Fife Voluntary Action, please contact info@fva.org

To contact Families in Trauma and Recovery please use: https://www.facebook.com/familiesintrauma/

To contact the Transforming Psychological trauma Implementation Co-ordinator in Fife please use fife.transformingtrauma@nhs.scot. More information on the National trauma training programme is available at https://transformingpsychologicaltrauma.scot/

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