

# The role of lived experience in creating systems change

**Evaluation of Fulfilling Lives:**  
Supporting people with multiple needs

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A report by CFE Research



This reports provides insights in to the different ways people with lived experience of multiple disadvantage contribute to creating systems change, the impact of their involvement on systems and themselves and how approaches might be replicated in different contexts. Since 2014 the Fulfilling Lives programme has supported nearly 4,000 people with experience of multiple forms of disadvantage, including homelessness, alcohol and substance misuse, reoffending, mental ill-health, domestic violence and physical and learning disabilities.

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For more information about the Fulfilling Lives programme visit [www.tnlcommunityfund.org.uk/funding/strategic-investments/multiple-needs](http://www.tnlcommunityfund.org.uk/funding/strategic-investments/multiple-needs)

For more information about the evaluation of Fulfilling Lives, including partnership-level evaluations, please visit [www.fulfillinglivesevaluation.org](http://www.fulfillinglivesevaluation.org)

## Key messages

An important part of changing systems is **changing attitudes and getting multiple disadvantage on the political agenda**. People with lived experience of multiple disadvantage (referred to here as experts) play a key part in awareness raising activities.

A key objective of systems change is to improve the help people receive. Potentially the **most powerful way for experts to create a lasting difference is through directly influencing the design and delivery of policy and services**. Involving experts in gathering and sharing evidence from current service users and planning new services or initiatives helps ensure services are designed to meet the needs and preferences of people affected by multiple disadvantage. **Experts provide a powerful and authentic voice** and unique insights that can challenge assumptions, motivate organisations to do things differently and pinpoint areas for change.

Making changes to policy and strategy can take longer to achieve than changing individual attitudes and involve many different actors. So it is hard to attribute precisely the influence of involving people with lived experience. Nevertheless, stakeholders gave examples of several policy and practice changes made by police, housing providers, local authorities and drug and alcohol services that they felt had resulted from learning and input from people with lived experience.

As well as influencing systems change, there are **positive benefits for the experts involved**. Experts gain valuable experience, develop confidence and feelings of self-worth and feel pride in being able to contribute. **Reframing negative past experiences** as learning to drive positive change can be empowering and satisfying. Interaction between service users and workers humanises the individuals on both sides, challenging stereotypes and potentially reducing power imbalances.

It is important to be aware of **potential negative impacts** for experts too. The repeated telling of their story can become a trigger for flashbacks or even relapse from recovery pathways. The external and internal pressures experts may feel to fix issues in the system they faced themselves can push them to take on more responsibility than they can deal with. A lack of knowledge of how their contributions have resulted in change or had an impact can demotivate and dishearten experts. Feedback for experts is often missing or can take a long time coming.

A key factor in ensuring that lived experience involvement is meaningful and not tokenistic is **ensuring that experts are kept informed and receive timely feedback. Even better, develop lasting opportunities for expert involvement**, such as a regular seat on a strategy board or continued engagement as policies are reviewed.

**Experts may need support** to contribute to systems change activities, though this will vary between experts. Support may include providing a contact experts know and trust, access to emotional support and a space for experts to share their experience with each other and provide mutual support. Practical support, including training in systems change as well as transferable skills, is also important. Experts' experiences and interests are varied. Matching experts' experiences to opportunities, including considering how recent their lived experience is, helps maximise the impact of their contribution.

Crucially, **organisations seeking the input of experts also need to adapt so that they make the most of the opportunity**. It is important to get buy-in to expert involvement across an organisation. This might mean providing training and sharing examples of the beneficial impact of involving people with lived experience. Organisations need to be aware of the power imbalances between staff and experts and consider ways to reduce these. Experts should be provided with detailed information in advance of any activity so they can prepare. **Co-producing systems change activities with experts** will ensure that the activity meets their needs and they can play an equal role, rather than being just another item on the agenda.

**Experts offer  
unique insights,  
challenge  
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## Glossary

**Co-production:** creating, delivering, improving and evaluating services jointly with people who will use them and stakeholders like local authorities, charities, frontline staff, funders, or academics.<sup>1</sup>

**Experts/Experts by experience:** are people with lived experience of multiple disadvantage who are using this expertise to bring about change to the systems that affect others facing multiple disadvantage.

**Involvement coordinators:** staff members who coordinate and facilitate the involvement of people with lived experience in systems change and co-production of services.

**Lived experience:** is direct, personal experience of a particular issue or service. In the case of this report this includes experience of homelessness, substance misuse, contact with the criminal justice system and mental ill health.

**Mobile ethnography:** is a type of research method. Researchers collect data from participants who use smartphones to record their everyday experiences, behaviours and feelings (using photos, videos or notes) in relation to a particular topic.

**Multiple disadvantage:** is defined in the Fulfilling Lives programme as experience of two or more of homelessness, reoffending, substance misuse and mental ill health. Many people will also experience other forms of disadvantage too.

**Navigators:** are service-neutral staff members who build trusting relationships with people affected by multiple disadvantage and support them to engage with a range of support and services as needed.

**Peer research:** is research that is guided and carried out by people with lived experience of the issue being studied.

**Stakeholders:** are organisations or individuals who have an interest in something. In this report we use the term to mean organisations whose work affects people experiencing multiple disadvantage. This includes local authorities, housing providers, healthcare providers, voluntary sector organisations, government agencies and other organisations that fund or commission services.

**Systems:** are formed of the people, organisations, policies, processes, cultures, beliefs and environment that surround each and every one of us.

**Systems change:** is a change to a system that is beneficial to people facing multiple disadvantage, sustainable in the long-term and is transformational (not a minor tweak to how things work).

# Introduction

Co-production and involving people with lived experience are at the heart of the Fulfilling Lives programme. All partnerships have groups of people with lived experience of multiple disadvantage who volunteer<sup>2</sup> their time to contribute to the work of the programme.

Creating lasting systems change – at local and national levels – is also a key objective of the programme. Lived experience groups have become increasingly involved in systems change work in their local areas.

Systems are the people, organisations, policies, processes, cultures, beliefs and environment that surround all of us. The Fulfilling Lives partnerships collectively agreed that systems change is a change to any of these elements that is:

- Beneficial to people experiencing multiple disadvantage sustainable in the long-term (in that it is resilient to external future shifts in the environment) and
- Transformational

Systems change is not:

- Tokenistic or minor tweaks to how things work
- Doing the same thing as before but under a different name
- Reliant on a few individuals

This report looks at how people with lived experience of multiple disadvantage – often referred to as experts by experience or simply experts – are involved in creating systems change, the impact of their involvement and how it might be replicated.

This research aims to answer three key questions:

1. How are people with lived experience contributing to creating systems change as part of the Fulfilling Lives programme?
2. What impact does involving people with lived experience in systems change activities have?
3. What needs to be in place for this type of work to be effective?

The report draws upon evidence from partnership staff, partner and stakeholder organisations, (such as local authorities, housing providers, voluntary sector organisations and government agencies) and insights and reflections from experts by experience involved in systems change activities. See page 30 for more details on the method.

This report will be of interest to local and national service providers and policy-makers whose work affects people experiencing multiple disadvantage. This encompasses the criminal justice system, local authorities, health services (including mental health) and the voluntary and community sector. Findings will also be of interest to funders and commissioners seeking to understand more about the role people with lived experience can play in creating effective systems and support.

## How are people with lived experience contributing to creating systems change?



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### Changing systems means changing attitudes

### Raising awareness and getting multiple disadvantage on the agenda

Improving the lives of people affected by multiple disadvantage needs systems to change across lots of different policy areas and at both local and national levels. To achieve this requires political will and a genuine wish to consider the needs of people experiencing multiple disadvantage. An important part of changing systems is changing attitudes and getting multiple disadvantage on the political agenda. This is never an easy task with so many other causes all vying for attention, but particularly so for a group often stigmatised and seen as undeserving.

Experts have been involved in a range of awareness raising activity. This includes: creating online content, radio interviews and podcasts, all with the aims of reaching a wide audience, raising the profile of the problem of multiple disadvantage and increasing public understanding.

**“ I really believe if this recording is listened to by decision makers and MPs, they may actually realise that we are ordinary people who are disadvantaged. Not only that, not only are we disadvantaged and struggling, we are often made to feel a hundred times worse by the people who are being paid to help us basically. *Expert***

Experts who took part in awareness-raising activities were positive about the experience; they valued the opportunity to share their experiences and were enthusiastic about the prospect of contributing to change. While the change resulting from these activities might be limited to those involved (in contrast to the wider changes achieved through engaging with service and policy design as described below), experts all felt positive after these events and believed that they would be successful in raising awareness. To maximise the impact of awareness raising, it is important that activities target and

reach those who can gain the most from them – that is, people with a lack of understanding of multiple disadvantage rather than those who are already knowledgeable and supportive.

## Gathering evidence and providing insights

There has been increased emphasis in recent years on ensuring public services are based on high-quality evidence.<sup>3</sup> Having convincing evidence is therefore important for influencing policy and practice. If evidence is to help improve services for people experiencing multiple disadvantage it is vital that the voices and experiences of those directly affected are properly represented.

**“ This type of research proves the successes of the [partnership] model and ethos which can then be used to promote it and educate services, funding bodies and professionals. To create change we have to capture the voice of those experiencing the failings in the system. *Expert***



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### Peer researchers help gather new insights

Some experts are trained as peer researchers to gather data through interviews and questionnaires. The researchers' lived experience puts them in a position to be able to empathise with people currently experiencing multiple disadvantage. As a result, experts say those answering questions are more likely to be honest about their experiences. In this way, peer researchers are helping to gather insights that might otherwise not be available to researchers without lived experience. Peer research can also help give a voice to those with relevant perspectives and experiences who may not be able to contribute to decisions about services more directly through formal activities such as board meetings and steering groups. For example, the report *Cause & Consequence: Mental Health in Manchester* was researched and co-produced by people with experience of homelessness and poor mental health and sets out a blueprint for getting mental health support right. All the recommendations from the report are being adopted locally.

Experts by experience mystery shopped local authority housing options services in Brighton and Hastings. After presenting as homeless and seeking assistance they reported on the environment, how they were treated and how informed the staff were. Both local authorities valued the feedback and implemented changes and improvements as a result. Fulfilling Lives South East in collaboration with Community Housing and Therapy provided training in psychologically informed environments for all staff in the Brighton and Hove housing department. As a result of the collaboration with Fulfilling Lives, the department began a review of staffing structures and delivery and have confirmed they will be making changes to the contract specification for emergency accommodation to enhance temporary accommodation options.

Mystery shopping is another way experts help to gather evidence on the appropriateness of services for people experiencing multiple disadvantage. People with lived experience test services and provide feedback on their experience.

Gathering evidence appears to be the most common way for people with lived experience in the Fulfilling Lives programme to be involved in systems change. While experts were generally positive about their experiences of doing research and mystery shopping, they also acknowledged that it could be more difficult for them to see an immediate impact from this type of activity. Therefore, it is important that experts who are involved in this type of activity are informed in a timely way about how research findings have been used and any changes that have resulted.

## **Influencing the design and delivery of policy and services**

Experts reported that although research can provide important evidence to stimulate and inform systems change, they feel they can have a more direct impact when contributing to the design and delivery of policy and services. They felt that without this higher-level influence, individual actions have limited impact.

**“ If services are aware of the difficulties a person who has a mental health problem is facing, then they can implement changes or they can try to have these changes done at a strategic level. This is where we need to start with systems change, so that it’ll filter down. *Expert***

Fulfilling Lives partnerships have helped to facilitate the involvement of people with lived experience in consultations on planned new services or initiatives. This allows experts to be involved from the outset and ensures services are designed with the needs and preferences of people affected by multiple disadvantage in mind. Engaging experts in this way also gives policy-makers an early insight into how their decisions may affect people experiencing multiple disadvantage and help identify potential problems with initiatives before they arise.

Opportunity Nottingham identified problems in the city caused by use of a synthetic form of cannabis, known as ‘Mamba’. People visibly under the influence of the drug were often slumped over and consequently vulnerable. The Council proposed using a dedicated ‘Mamba Car’ to respond to these incidents. However, consulting with experts demonstrated this would likely be a wasted effort. By the time a response could be mounted to pick up an individual under the influence of Mamba, the drug would have worn off. Experts suggested investing in other services to support people instead. Consulting experts brought a more realistic perspective, and stopped the implementation of a well-intentioned but potentially costly intervention with likely limited impact.

As well as one-off and time-limited consultations, some experts have achieved permanent positions on committees and strategic boards. These include national public health committees, mental health trusts, a local drug-related death taskforce, homelessness partnerships and a group working towards drug and alcohol management and harm reduction. By having a permanent position, the lived experience perspective becomes an ongoing and formalised part of the policy and decision-making rather than a one-off consultation. This illustrates evidence of a willingness to share power and recognition of the value and importance of the perspective of people with lived experience. This, in itself, is as an important form of necessary systems change.



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## Engaging experts is only effective if decision-makers act on their comments

Fulfilling Lives partnerships have played a key role in linking experts from their networks with commissioners and service providers to inform ongoing service planning. Indeed, Fulfilling Lives partnerships have created some of the groups to which experts belong. Being able to influence service commissioning is a significant step to sustainable systems change.

A key objective of systems change is to improve the help people receive. So, influencing the design and delivery of support services and the policies that guide them can appear to have the most tangible link to systems change. However, engaging with experts is only effective if decision-makers take on board their comments and act on them. Experts who were involved in activities designed to directly influence the design of policy or services were overwhelmingly positive after the event about their contribution. Most were happy that they had participated and all reported that they felt there would be an impact on services or policies because of their involvement. The examples gathered as part of this study appear to be more than just tokenistic consultation.

# The impact of involvement in systems change on experts

## Positive impacts on experts

We found that involving people with lived experience in systems change activities can be a very positive experience for them. All the experts who took part in this research reported being 'happy' or 'excited' before and after attending systems change activities.

For many of those with lived experience, contributing to systems change is an important part of their life and contributes to their recovery. The systems change activities they take part in help them to develop a track record of experience in the sector and add to their CVs. Volunteering their time in this way provides structure to their day and a meaningful way to spend their time.

Experts' participation in systems change is also viewed as a means of giving something back to society. The satisfaction experts feel from contributing boosts their confidence, creates a sense of pride and self-worth and keeps them motivated. It can be powerful for experts to recognise that their actions and their words are being listened to and their contributions can have a positive effect.

**“** You feel like you're involved and you're part of something. You feel like you're having your input into changes in the future. It just makes you feel great in yourself. Yes, it does. It just gives you so much self-motivation. *Expert*

**“** When being involved in change, as an expert, it can give you a sense of pride. That your experience is valid, that there is a hope to improve the service for future experts. *Expert*

Fulfilling Lives partnerships are able to respond quickly and appropriately to requests for expert input by maintaining teams of volunteers with lived experience. The teams help create a sense of community amongst experts. Within that community, experts can share experiences, informally support each other, provide appropriate challenge to one another and form lasting friendships.



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**Contributing to systems change boosts confidence and self-worth**

Just as stakeholders' preconceptions of multiple disadvantage are challenged by interacting with experts (see following chapter), experts also have the opportunity to see frontline workers and policymakers in a different light, particularly crisis response teams whom experts may have had negative experiences with in the past. Interaction between service users and workers humanises the individuals on both sides, challenging stereotypes and potentially reducing power imbalances.

**“** I've seen a different side of services... instead of thinking oh they're all 'bleeps', you know, it's about that, addressing that balance and trying to understand each other's perspective. *Expert*

## Challenges for experts

Experts do not always receive sufficient information in advance about the purpose of the activity they are invited to and what is involved. If not briefed before taking part in activities, experts are likely to feel more isolated and unprepared – going into an event with no idea of what their role will be can be nerve-racking. Since experts are also invited to one-off events, as well as recurring activities, going into an unfamiliar environment with unfamiliar faces can also be challenging.

The external and internal pressures experts may feel to fix issues in the system they faced themselves can push them to take on more responsibility than they can deal with. The volume of requests for lived experience involvement from stakeholders can be very high and can result in experts experiencing burnout.

**“** I have a habit of doing a lot so whilst I have agreed to help out today, other projects are on my mind as well as personal issues which are unavoidable but I can carry on. I worry that I am not my best, my concentration is affected but I haven't found a balance yet. *Expert*

Unless due care is taken in supporting experts as they participate in systems change, the repeated telling of their story can become a trigger for flashbacks or even relapse from recovery pathways.



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## Experts' identity is more than their lived experience

“ One of the Fulfilling Lives [mystery shoppers] who did come in with a scenario of actually meeting with a Department for Work and Pensions worker and saying 'I'm fleeing domestic abuse', she actually had suffered domestic abuse in the recent past. Going through that scenario, coming into the Jobcentre, they were actually in tears by the end of it. *Stakeholder*

This risk is not always recognised by organisations seeking expert input.

“ There are still some service providers, policy-makers, change-makers, commissioners that literally will just wheel somebody out at the eleventh hour to say, 'Yes, I've ticked a couple of boxes,' and then off they go again, and no understanding of the trauma that they could have caused by asking that person with lived experience to share their story. *Partnership staff member*

A lack of knowledge of how their contributions have resulted in change or had an impact can demotivate and dishearten experts, particularly if they have shared their personal stories. Fulfilling Lives involvement leads and experts recognise that change takes time, but some communication about the impact of experts' involvement would be beneficial.

“ It... might feel a bit tokenistic, [stakeholders] don't really feedback on what they've done with [expert] responses. That makes people feel disheartened... when you feel like you've been advocating for something. *Partnership staff member*

Experts sometimes can feel like their identity is wholly dictated by the 'lived experience' label, and their opinion is valued only because of this. This is only part of their identity and experience and they have other skills and attributes to contribute. It would benefit all if those working with experts were mindful of this.

# The impact of involving experts on systems change

## Changes to individual awareness, attitudes and perceptions



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### Experts help challenge stigma

The impact most frequently mentioned by experts and staff was improving people's awareness of, attitude towards and understanding of multiple disadvantage. Involving people with lived experience in systems change activities means the voice of experts is heard by a wide range of people, from politicians to senior managers and staff delivering services.

By talking openly and honestly about their experiences and answering questions, experts can help to demystify what multiple disadvantage means and challenge stigmatising perspectives. Face-to-face interaction and personal testimony can have a highly powerful, and therefore lasting, impact on participants. Hearing directly from experts can bring to life issues that might otherwise be discussed abstractly and help people to see the human story behind facts and figures.

Experts themselves were most likely to highlight changes in attitude as the main impact of their participation in systems change activities. This may be because this type of impact is the most immediately visible to those involved. The link between expert involvement and wider or longer-term changes can be harder for them to see; their diaries after attending events use words and phrases such as 'hope', 'aiming to' and 'seem to' when discussing what change might happen as a result of their involvement.

The need for cultural change is often mentioned as a key requirement for systems change. Therefore, a shift in attitudes is a crucial and necessary foundation, to produce impact in terms of changing policies and guidance necessary for sustained change.

**“ We recognise that this is a journey, and this transformation is a journey in the way that we can't just have a neat action plan and have a whole lot of things ticked off. This is about changing people's attitudes. *Housing stakeholder* ”**

Experts understand that culture change will not be immediate, but that they play a key role in the vital first step of changing attitudes to and increasing awareness of multiple disadvantage.

**“** The people who I spoke to today were professionals at a strategic level... and I think if any of them take my view from my perspective on drug-related deaths on board, then yes, I think it's a positive change for disadvantaged people. It's not going to happen overnight. It's a cultural change and this takes time. *Expert*

VOICES (Voice of Independence, Change and Empowerment in Stoke-on-Trent) co-designed a series of bespoke workshops with Expert Citizens CIC for local A&E staff. These were co-delivered with an expert who has lived experience of co-occurring mental ill-health and substance misuse along with homelessness. The learning opportunities aimed to reduce stigma and to provide a better understanding of the barriers experienced when accessing services for people experiencing multiple disadvantage – such as difficulties with GP registration, access to mental health and social care assessments and welfare benefit applications. Staff found hearing the expert's first-hand testimony particularly useful.

**“** [He] described how he'd felt when he was here. What he fed back was how he felt neglected and left in a corner and abandoned... it was really, really powerful... the attitude stuff I think was a direct impact on the staff, and not really something I could replicate. *Healthcare stakeholder*

As a result of the sessions, A&E staff reflected on their assumptions about people experiencing trauma who are of no fixed abode. Homelessness resource boxes were added throughout the department and VOICES with Expert Citizens CIC went on to deliver further learning opportunities to hospital staff that included Trauma Informed Care and Psychologically Informed Environments.

## Changes to the way services are provided

Stakeholders in a variety of roles gave examples of improvements to ways of working and service delivery that had happened as a result of lived



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## Experts remind us that people experiencing multiple disadvantage are individuals

experience input. For example, one partnership had merged drugs and alcohol misuse services as a result of involving experts in the design phase. In another area peer research showed that some support services were ending support before beneficiaries felt they were ready. As a result of these findings the services concerned ensured beneficiaries were consulted before support was ended.

Staff changing their working practices can be an immediate result of frontline staff attending training sessions or workshops delivered by or involving experts. One partnership spoke about the impact of training workshops with the police, involving experts sharing their experiences of police custody. This led to changes in custody procedures for those experiencing a mental health crisis. People experiencing mental health crisis are now taken to a healthcare setting instead of being detained in a custody suite.

**“** Section 136 power [...] essentially, it is the power to detain someone who seems to be in an acute crisis, a mental health crisis. That power would usually mean someone being detained in a custody suite. They have managed to reduce that now, and no one under Section 136 gets put into a custody suite. They've all been put into a healthcare setting, which is a huge change. *Partnership staff member*

One of the impacts of involving experts is to remind stakeholders that people experiencing multiple disadvantage are individuals, with individual and diverse needs. Encouraging frontline workers and other stakeholders to recognise this can be particularly effective in changing the way they engage with service users. Hearing the authentic voice of lived experience appears to be key here.

**“** [Hearing real-life experiences is] reminding quite a few of us around the table that this is not about imposing our own cultural norms onto other people. It's actually identifying what the cultural norms are for each individual, and how do we work within that. So what some people might find acceptable, or expectations, if you like, of what success is, actually differs. *Jobcentre Plus stakeholder*

Experts have a vital role to play describing the experience of using services. This can be particularly helpful in understanding why some people leave services or do not use them in the first place. Too often, a lack of engagement

with services is seen as a problem with the individual rather than the service. Hearing from service users directly can motivate organisations and their staff to do things differently to encourage engagement.

**“** ...it's very easy to say people weren't engaged [with our services]. What we wanted to do is challenge [frontline staff] to think of more creative ways of doing. *Local authority stakeholder*

Practical changes have been made to service delivery in response to direct feedback from people with lived experience including changing opening times to be more convenient for service users and making environments more welcoming. For example, a mixed-sex hostel was changed to be male-only after senior managers at an event heard the negative experiences of a female expert who had spent time living there.

People with lived experience can also enhance service capacity and help make services more effective by getting involved in delivering support themselves. As the example below illustrates, the often-unique experience of experts means they can reach people and build trust where it can be harder for people without lived experience to do so.

In Blackpool, members of the Fulfilling Lives lived experience team sit on a variety of strategic committees for the area, including the Drug Deaths Review Taskforce. The lived experience team bring knowledge of street drug use in the town. They highlighted that there were a large number of users not able to get the opiate reversal drug Naloxone, used in suspected overdose cases, as they were not registered with drug services. The input of experts led to a change to local drug service practice. Members of the lived experience team were trained to administer the drug. Their experience means they are trusted by and can reach drug users who are not otherwise working with services.

**“** We're able to go out and give it to people on the streets, get into the crack houses, the dens where your normal workers can't get to. All of the guys that I've got on my team are mainly from Blackpool, I'm from Blackpool, I'm an ex-drug user in Blackpool, so everyone knows and trusts us, when you go out on the streets to speak to them. *Partnership staff member*

## Changes to policy and strategy

Changes to service delivery as a result of expert input are encouraging. However, to prevent these being reversed, changes need to be formalised in the structures and policies that shape and guide what happens across different organisations, sectors and localities. We found examples of ways of working becoming formalised in practice guidance and standards that have been developed in close collaboration with experts.

**“ The development of our practice guidance around engagement has been designed by people with lived experience, and it’s impacting upon our staff daily. Our frontline practices pick that up on a daily basis, and it’s about how people engage with people. *Local authority stakeholder***

As new ways of working are seen to be effective, there can be a ripple effect, with changes being adopted by different organisations across a local area. Impact can start small-scale and grow outwards. One example of this is a city-wide pledge by services to cater better for people experiencing multiple disadvantage and adopt the navigator model<sup>4</sup> of supporting people. As well as explaining why some services are not working and how they could be improved, people with lived experience have played an important role in capturing evidence on what does work, which strengthens the case for replicating effective practice elsewhere.

The Fulfilling Lives Newcastle and Gateshead Experts by Experience Network have done a number of peer research projects on behalf of various services to shape future models of working. One project examined the user experience of 'Together in a Crisis', a proof of concept service led by Mental Health Concern designed to provide support for people in crisis, but who do not meet the criteria for the local NHS mental health crisis service. The Experts used their ability to build rapport with and talk openly to recent service users to get their views on the service. Feedback was positive and the final report including peer research findings was used to secure further funding and a wider roll-out of the service.

Making changes to policy and strategies can take longer to achieve than changing organisations and services, and involve many different actors.

And so it is hard to attribute precisely the impact of involving people with lived experience in this type of change. Nevertheless, stakeholders pointed to several policy changes made by police, housing providers, local authorities and drug and alcohol services that they felt had resulted from learning and input from people with lived experience.

“ One of the big things that’s come out of the work that we’ve done with Fulfilling Lives and with experts by experience is [to] acknowledge that we need to do more early help work. That has really come out into our strategic plan, and it’s going to be something that we’re really going to focus on over the next five years, as part of our strategic plan... [experts] say that we’re sick of having to wait until crisis point, we need help earlier. *Local authority stakeholder*



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## The authentic voice of lived experience can be powerful

Commissioners, policy – and decision-makers may rarely get the opportunity for direct contact with people with lived experience of multiple disadvantage. The authentic voice of experts can provide a different and more detailed perspective. This can help to put policy and service provision into context for stakeholders and make them more aware of how their decisions affect people’s lives.

Experts are often refreshingly straight-talking and to the point with their contributions. Policy-makers often welcome the fact that the perspective of people with lived experience can help to clearly and directly pinpoint issues for change.

“ A few of the [board] members have been talking about simple solutions but potentially complex problems. That is something that I’ve started to hear more and more... the [meetings] that experts have been at consistently look at [problems] in a much more simple way rather than getting it overly bogged down with policies and bureaucracies saying, this is the bit that needs changing and it’s a bit of a lightbulb moment. *Fulfilling Lives staff member*

Almost all of the reported impacts on policy happened as a result of ongoing relationships built between partnerships, experts and stakeholders through recurring meetings and consultations. The ongoing involvement of people with lived experience, particularly where this is formalised through regular

meetings, appears crucial for systems change. Only involving experts in one-off events can be seen as tokenistic and less impactful.

One of the impacts of successfully involving experts is that it can lead to greater commitment to co-production in the future. Engaging with experts and seeing positive changes as a result of their input can help to overcome any initial scepticism stakeholders have about the value of lived experience in informing service design. Stakeholders and Fulfilling Lives staff acknowledged that, although co-production is still not fully understood by many decision-makers, the genuine involvement of lived experience is becoming more widespread. Experts are now involved in more decision-making processes than before.

**“** For me, it's just, a standard way of working, or whenever we develop something new... we'll work alongside [experts] to make sure that they're involved. I wouldn't say it's perfect but we've started on the journey, and it's become a bit of a principle now, that anything we do, we work alongside with lived experience. *Local authority stakeholder*

In some cases, commitment to co-production is being formalised through, for example, a coproduction accreditation programme for services that further ensures that these changes are long-lasting and sustainable.

# What needs to be in place for lived experience involvement in systems change to be effective?

## Support for experts

Experts and their lived experience can be a catalyst for change. For this to happen, people with lived experience need to feel supported before, during and after their involvement with systems change activities. Rather than assuming that all experts need a large amount – or even any – support, support needs are best considered according to the individual and the activity.

## Consider and monitor the potential risk of harm to experts

As described in the previous chapter, sharing experiences or being reminded of difficult times can lead to experts feeling distressed and potentially increase the risk of relapse from recovery pathways. Fulfilling Lives partnerships are careful to monitor experts' recovery and provide support. Experts must not be pressured or expected to share their personal experiences if they do not wish to. Finding out what experts are comfortable with sharing, perhaps in an informal meeting beforehand, is important to safeguard experts against further harm or distress.

## Tailor support to meet individual needs

Tailored support is offered by all partnerships to all experts involved in systems change work. As touched upon previously, experts' needs are unique and the level of support required will vary, which is why experts should be consulted on what support they want and need. When experts feel ready to attend activities alone or with minimal support, this should be encouraged. Allowing experts

the autonomy to take control of their contribution can build confidence and be empowering for them. By providing tailored support, experts are more likely to feel supported and remain engaged in systems change work.

## Ensure experts have a contact they know and trust

Successful involvement of people with lived experience in systems change is, to some extent, reliant on the development of trusting relationships between managers/mentors and experts. This relationship is central to safeguarding experts against harm and ensuring their support needs are met. Experts need to know who to talk to and feel comfortable speaking up if they are being asked to do too much. Most, if not all, partnerships have an involvement lead/coordinator or mentors who fulfil this role. Informal meetings provide the opportunity to check-in with experts and for experts to raise concerns, worries or ask questions.

**“** I always offer people regular, you know, ‘Let’s go out and get a coffee’, ‘Do you want to talk to somebody?’, ‘Do you want to skip that meeting?’, ‘How are you feeling?’, ‘If you don’t want to go to something on the day, just... text-message’. And it’s building that trust. Then hoping that, should they need something, they’ll say something. *Partnership staff member*

## Offer access to emotional support

Several partnerships also offer support in the form of access to a counsellor or a psychologist with whom experts can speak in confidence. This can be related to involvement in systems change activities or general mental wellbeing.

Several partnerships offers wellbeing workshops, where partnership staff members can get to know their experts on a personal level, understand their experiences and their responses to different situations. The workshops and similar expert network groups organised by other partnerships are an informal method of safeguarding experts. They also offer a space where experts can get together and discuss any challenges they are facing so these can be acknowledged, and allowances made if necessary.

## Provide a space for experts to share experiences

Many partnerships facilitate expert involvement in systems change through groups of volunteers. A sense of community between experts arises as a result of membership of these groups. Within that community, experts support each other and form lasting friendships. Providing an informal space for experts to socialise and share their experiences of taking part in systems change can have several benefits, including: developing a collective voice through challenging their own beliefs; being able to see their own and others' strengths; and recognising the impact they have on systems change.

**“** You also see that within the network they, kind of, form like a community bond, where they support one another, and they can challenge one another, recognise each other's strengths. *Partnership staff member*

## Give detailed information in advance of an activity

Earlier in the report we highlighted the negative impact of experts not receiving sufficient information in advance of an activity or being prepared. Experts feel better prepared if they are given as much information as possible before a systems change activity takes place. This includes information about who will be in attendance/speaking, and the agenda and purpose of the activity. Briefing experts beforehand also provides the opportunity to discuss and establish boundaries for experts' involvement. Experts should be heavily involved in these discussions.

## Match experts to opportunities

Experts' experiences and interests are varied. The impact is likely to be greater where experts are matched to activities most appropriate to their experience.

**“** We've all got different expertise. We can look at an event and look at what's going to be discussed and see who's lived experience best suits that event. Whose voice is going to be best heard in that situation? Who is the real expert about that situation? *Expert*



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## Consider recentness of lived experience when matching experts to opportunities

All lived experience is valid. But how recent that experience was can make a difference to the type of contribution that is most appropriate. Very recent experience of using services is more useful for contributing to discussions about specific systems and services and how they could better meet the needs of people with lived experience. Services and the wider context in which they operate changes over time. The way someone experienced a service some years ago may not reflect current practice and so older experience may be less relevant. Some stakeholders also perceived that recent lived experience results in a more committed expert.

“ The further people go away from that lived experience then I think the rawness or the hurt that they still very often feel isn't conveyed in their work. These are people who have a real passion for other people not to be treated in the way that they were so often by the system. That recentness is really powerful. It dilutes a bit the further away you go from that. *Voluntary sector stakeholder* ”

Historical experience can still be valuable in understanding, with hindsight, the factors that have helped someone to progress with their recovery journey and how the system can support that.

“ That person from five years ago has an extreme value because actually it's about their experience and what helped them get to a point where they were seeing themselves as being successful or achieving outcomes or whatever it might be, because we need people who have actually have lived outside of the system as well. *Local authority stakeholder* ”

Fulfilling Lives involvement leads are well placed to suggest suitable experts for systems change work, and account for any specific criteria stakeholders may have, such as having experts who have experience of rough sleeping or the justice system. Fulfilling Lives partnerships consult their pool of experts when choosing who might take part in upcoming activities, ensuring that the same expert is not chosen repeatedly. They brief experts about activities they have been invited to, helping them decide whether the opportunity matches their experience and skills. Expanding the pool of expert volunteers also means partnerships have a more diverse range of expertise to draw from.

## Help experts to represent the views of others

Experts' experiences and views are all individual, and yet experts are expected to represent the wider interests of people affected by multiple disadvantage when taking part in systems change activities. Fulfilling Lives partnerships have attempted to support experts to share collective rather than individual perspectives.

**“** When sharing experiences, and stories it is always 'we', as I don't walk into an opportunity as me, I am a representative of the voice of lived experience. *Expert*

Partnerships hold briefings with their expert groups to gather insights that can be shared during systems change activities by those taking part. They also train experts to carry out peer or street research to gather insights from those currently experiencing multiple disadvantage.

## Provide practical help to get to and take part in activities

Providing practical support to experts is also important in helping them to prepare for and attend events. Several partnerships provide transport to and from venues and remind experts about events they are due to attend. Being accompanied by a Fulfilling Lives team member can help to overcome safeguarding challenges. For example, if other attendees do not fully understand the needs of those with lived experience, situations can arise which experts find difficult to manage. In these instances, the presence of a Fulfilling Lives team member can provide reassurance and a much needed familiar face.

The COVID-19 pandemic has highlighted in particular how not having access to a mobile device, such as a phone or tablet, can be a barrier to engaging in systems change networks and activities. Partnerships have helped to address this digital exclusion by providing experts with the equipment they need to fully participate.



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**Not having a mobile device can be a barrier**

## Offer training in systems change

Training is important in providing experts with an understanding of what systems change is and how they can contribute to change. Training is recommended for all who engage in systems change activities throughout their journey as experts and they will benefit from topics such as:

- The concept and meaning of systems change
- The different ways in which people with lived experience can contribute to systems change
- The role of different stakeholder organisations operating in the multiple disadvantage sector
- Widely used jargon and acronyms

Training in these topics will help experts to feel comfortable and make a confident contribution. They will understand the purpose and aims of systems change and the wider context in which they will be contributing – including how services and decision-making works and key terminology they will come across.



I contributed throughout the day. I brought up a lot of the values of co-production. I spoke about solution-focused practice, scaling, the Power Threat Framework. All these things I've learnt when training with Fulfilling Lives and I was able to use the skills I'd learnt there today [at the systems change event]. *Expert*

## Provide opportunities to develop transferable skills and confidence

As outlined throughout this report, experts have a unique contribution to make to systems change activity. It's important to harness this by providing training and support to develop the confidence and skills needed for systems change activity. Partnerships offer training that includes formal sessions focusing on specific skills, such as communication and presentation skills as well as informal training delivered through regular meetings and mentoring. For example, volunteers from Fulfilling Lives South East joined a procurement panel with Brighton and Hove Clinical Commissioning Group (CCG)

interviewing providers for a Homeless Healthcare Hub in the city. Fulfilling Lives provided training so they felt confident to interview and assess expert clinicians in a professional manner. The independent assessor fed back that the interview was the best he had taken part in.

Most, if not all, partnerships offer experts access to formal training to support their personal progression. This includes assistance with writing job applications, mock interviews, work experience and guidance on managing finances. Ongoing training like this provides experts with an added incentive for their sustained involvement in systems change activity.

## Organisational change

As previously described, organisations seeking the input of experts need to ensure that the voice of experts is heard and acted upon. To maximise the chances of successful expert involvement, it is recommended that organisations take the following steps.

### Aim to sustain and embed expert involvement

Co-production and involvement of people with lived experience in systems change should be an ongoing activity. Experts are wary of being invited to events they perceive as a tick box exercise, and suggested avoiding this by planning follow-up involvement:

**“ Give us tasks to do, give actions to take away and keep us informed along the way, and we would obviously know that we’re needed, not because we’re a tick-box. *Expert***

Sharing personal histories and experiences is only one part of the process and should not be the whole purpose for experts attending events and other systems change activity. While individual stories can help to illuminate issues and barriers, the real value of these experiences is to act as a prompt for discussing and instigating change.

Expert involvement in planning and decision-making needs to be embedded at a strategic level. This ensures, it is not an add-on but becomes part



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## Mandating expert involvement needs careful monitoring

of the usual way of working. Collaboration and co-production are central to the systems change work that experts are involved in. This involves a shift in the thinking and practice at individual, organisational and policy levels.

The co-production working group from Fulfilling Lives South East, like other partnerships, is developing a model for co-production, which it plans to integrate into policy in the local area. This is an important shift in embedding co-production across the system.

There are mixed views about the value of mandating lived experience involvement in projects and services. Experts, in particular, expressed some concerns. They were concerned at the possibility that, if mandated as part of service commissioning, expert involvement could become a box-ticking exercise or another hoop to jump through, and the experts' participation may be resented. In some cases, the mandatory involvement of people with lived experience has been fulfilled by seeking feedback from individual service users and not from the outset. However, without mandating involvement, there is a risk that it does not happen at all. If lived experience involvement is made mandatory in grants and service contracts, it must be carefully assessed and monitored to ensure collaboration and co-production is at the heart of activity and not an add-on. Sharing good practice guidance and examples may help with this.

## Ensure buy-in to expert involvement across the organisation

Expert involvement can be short-lived if commitment to involvement is reliant on a few key people in an organisation. One of the challenges to expert involvement is gaining buy-in from staff at all levels. Understanding of what co-production is and how to do it properly is not yet widespread among stakeholders. Developing this will require time and effort.

**“** [...] sometimes you will get a bit of push-back, a bit of a roll of the eyes thinking, ‘Oh, joke,’ and you’re, like, ‘No, actually we want to do this well, and that means it might take a bit of time, but my God, the taking time will really reward your services’ [...] I think that’s probably been the biggest challenge for us [...] because everyone’s at different levels of understanding of what co-production actually is. *Partnership staff member*

Fulfilling Lives partnerships play an important role in ensuring buy-in. This is done through developing relationships with stakeholders, guiding them through the process and ensuring their plans for involving experts are appropriate.

## **Provide training on the principles and practice of expert involvement**

Partnerships offer training to stakeholders on the principles of engagement and how best to involve people with lived experience in systems change activities. This helps to address the apprehension some stakeholders may have about involving experts. ‘Soft skills’, such as knowing when to encourage an expert who is struggling to express their opinion, may not be immediately available to stakeholders without appropriate training. As previously identified, stakeholders need to know how to support experts without pressuring them to share anything they do not want to.

## **Share examples of the benefits of expert involvement**

Stakeholders may be sceptical about the value of involving people with lived experience, particularly given the time, resource and expertise required to do it properly. Engaging with experts and seeing positive changes as a result of their input can help to overcome this. Sharing examples of how expert involvement has improved services can help to create buy-in.

“ These kinds of processes in other organisations, they depend on drive from 1 or 2 particular people who get it and see it. At the moment, we have a number of us here who are really committed to driving this forward. We would hope that as change happens, we’re bringing other people on board. *Housing stakeholder*



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## Keep experts informed about the impact of their contribution

### Keep experts informed of progress and provide timely feedback

The point made most strongly by experts was the importance of being kept informed of progress and receiving feedback after they have taken part in an activity. Experts rarely receive detailed feedback about their involvement or any follow-up actions resulting from an activity, which can be disheartening. Fulfilling Lives team members – especially involvement leads – are unlikely to discover what impact experts’ involvement has had on systems change unless they actively seek this information. This leaves both experts and partnerships feeling frustrated.

“ That’s what it all boils down to, feedback... because then you know that it’s been took on board and something has happened with it. So if you don’t get the feedback you don’t know if anything has happened with it do you? *Expert*

Stakeholders are perhaps best placed to observe how the involvement of people with lived experience has influenced their decision making and changes in policies, procedures and practice. It is important that they let experts know how their contribution has been used. This helps ensure a more meaningful and satisfying experience for experts, as well as ensuring that progress has been made towards change.

### Reduce power imbalances between experts and other stakeholders

It is important that power imbalances between experts and other stakeholders are addressed so that the voice of lived experience can

be heard and is valued. Active consideration needs to be given to how power imbalances are signalled to avoid unintentionally alienating experts.

**“ I don’t think people always necessarily invite people onto boards and committees... for them to be a token, but sometimes... you just don’t realise you’re bombarding them with ‘We’re all senior people, and I’m wearing a suit and that makes me important, and you only get the ten-minutes at the end’. Stakeholder**

Addressing power imbalances means planning the involvement of experts thoroughly in advance. Experts said that at some activities they had attended in the past, the purpose of the event was not clear, their contribution had not been built into the agenda and insufficient time had been allocated for their participation. Support from Fulfilling Lives partnerships to organisations seeking the help of experts can go some way to addressing this.

**“ I really got the feeling from the [Fulfilling Lives] staff that we spoke to, that everything [the experts] did had to be okayed by the team, they had be comfortable, they wanted to make sure our facilities were right and our attitude was right, and our staff were told about what to expect and things, so I think that protection’s very important. Stakeholder**

Holding meetings or consultations within professional or administrative buildings can be intimidating for experts and require them to adapt to a different culture. Instead, to alleviate some of the intimidation and/or anxiety, it is beneficial to hold meetings in spaces that are more familiar to experts, such as service user hubs or other informal community venues. Involving experts in planning as well as attending an activity can also be helpful. This ensures that the content and structure works for them.

**“ We worked alongside the experts by experience in planning the workshop, as well, so they were fully involved in deciding how we would go ahead with it. They opened the workshop. They did a quiz in terms of what myths there were around safeguarding, and what myths there were around access and services. It was absolutely brilliant, it really opened everyone’s eyes. Local authority stakeholder**

## Concluding comments

In this report we aimed to bring together two key elements of the Fulfilling Lives programme – expert involvement and systems change. We collected experts' thoughts and feelings before and immediately after they attended systems change activities and captured their reflections on their experiences and the difference their contribution makes in creating systems change.

Working closely with the experts, we have seen their commitment and passion to make a difference for others. We have also been impressed by their thoughtful insights, their considered and committed approach to the project and their frank but constructive feedback. Our work has benefitted from their input. It is clear from the evidence gathered other organisations who have engaged with the experts have benefitted also.

Experts believe that their contributions lead to better support for people experiencing multiple disadvantage. We recognise that systems change does not happen immediately and can be a gradual process. But we have also seen how the testimony of experts can have a profound impact on those hearing it. Experts too, if properly supported, can benefit from using their particular experience to help others. Bringing together those who provide and use services helps all parties to see each other as fellow individuals. The hope is that an accumulation of smaller changes in attitude and approach may build to something more transformational. As one expert put it:

 **It's not going to happen overnight. It's a cultural change and this takes time. But baby steps, a little bit at a time.**

We have learnt much from working with the lived experience experts on this study. We hope that by capturing some of the key lessons they and other stakeholders shared with us, that this report will help others to involve experts in a way that is meaningful and has a positive impact – both on the system of support for people experiencing multiple needs and the experts. Involving experts requires thought, time, resource and expertise. It is not about handing over control, but drawing on a range of people with different perspectives, ideas, experiences and skills to help create something better.

Afford experts the respect they deserve. They know, perhaps better than anyone, what it is like to need help, to look for support, to use a service.

They are also experts in why that can sometimes be a frustrating and unpleasant experience. Their expertise is crucial. We need to make more and better use of this.

## About this research

This research was conducted during October 2019 – May 2020 and was based around a participatory approach where experts took part in mobile ethnography to record their contributions to system change activities.

19 experts involved in systems change activity across eight Fulfilling Lives partnerships signed up to take part and attended an initial training workshop. Those who had a compatible smartphone (all but one) downloaded a customised app that encouraged them to record their thoughts before and after attending events, meetings or other activities that had a systems change link. Questions prompted them to think about what their contribution had been, how it was received and the impact that their attendance might have. This method allowed the evaluation team to gather instant reactions and reflections on events in real time. We offered those without access to a smartphone a paper version of the app questions along with use of a voice recorder and disposable camera, so they could still participate and record their experiences.

Nine experts who had contributed the most data through the app were interviewed afterwards to explore some of their experiences in more depth.

Data gathered from experts was supplemented with:

- Desk review of partnership evaluations and monitoring reports
- Telephone interviews with 13 partnership staff, including all lived experience leads
- Telephone interviews with 10 stakeholders from local authorities and other organisations who had worked with expert groups in partnership areas

A workshop had been planned to analyse the data together and co-produce findings with the experts. Due to the COVID-19 pandemic this had to be cancelled and the smartphone app was instead used to suggest themes and ask experts to feed back their thoughts on the emerging findings. 11 experts participated in this and their responses are reflected in this report.

## About Fulfilling Lives

The National Lottery Community Fund is investing £112 million over 8 years (2014 to 2022) in local partnerships in 12 areas across England, helping people with multiple needs access more joined-up services tailored to their needs. The programme aims to change lives, change systems and involve beneficiaries. The programme is not a preventative programme, but instead aims to better support those with entrenched needs who are not otherwise engaging with services. The programme uses coproduction to put people with lived experience in the lead and builds on their assets to end the revolving door of disjointed care for adults. The programme also has a strong focus on systems change, so that these new ways of working can become sustainable.

## Useful resources and further information

### Co-production and lived experience

[A meeting of minds: How co-production benefits people, professionals and organisations](#) (The National Lottery Community Fund, 2019)

[Co-production champions – reflecting on the first four months](#) (WY-FI, 2018)

[Co-production information sheet](#) (The National Lottery Community Fund)

[Co-production training](#) (Fulfilling Lives Newcastle and Gateshead)

[Lived experience discussion paper: The Independent Futures \(IF\) group experience](#) (Golden Key, 2017)

[The value of lived experience](#) (Blackpool Fulfilling Lives, 2019)

[What does co-production look like in a time of crisis?](#) (Fulfilling Lives Newcastle and Gateshead, 2020)

### Peer research and co-produced outputs

[Access to primary care services for patients with “no fixed abode”](#) (VOICES, 2018)

[Become a peer researcher](#) (Fulfilling Lives Newcastle and Gateshead)

[Cause and consequence: Mental health and homelessness in Manchester](#) (Inspiring Change Manchester, 2019)

[Local evaluation peer research discussion paper: The client experience](#) (Golden Key, 2017)

[‘In it together’: Finding the power and strength in peer research](#) (Inspiring Change Manchester, 2019)

Peer led research: Principles and outcomes  
(Inspiring Change Manchester, 2019)

Views and experiences of local mental health services for people with experience of homelessness or insecure housing  
(Fulfilling Lives Newcastle and Gateshead, 2019)

## **System change**

An action experiment approach (Golden Key, 2019)

Evaluation of Every Step of the Way Experts by experience and systems impact (Birmingham Changing Futures Together, 2019)

Fulfilling Lives: Changing systems for people facing multiple disadvantage  
(2019)

Local evaluation phase 3: System change (Golden Key, 2019)

Systems change prospectus (VOICES, 2017)

Theory of Systems Change (Fulfilling Lives South East)

## **Other**

Multiple disadvantage learning opportunities (VOICES)

True stories of people facing multiple disadvantage  
(Fulfilling Lives national campaign)

## Endnotes

1. Woodall, J. Davison, E. Parnaby, J. and Hall, A. (2019) A Meeting of Minds: How co-production benefits people, professionals and organisations. National Lottery Community Fund [www.tnlcommunityfund.org.uk/media/A-Meeting-of-Minds\\_How-co-production-benefits-people-professionals-and-organisations.pdf?mtime=20190919092658&focal=none](http://www.tnlcommunityfund.org.uk/media/A-Meeting-of-Minds_How-co-production-benefits-people-professionals-and-organisations.pdf?mtime=20190919092658&focal=none)
2. Partnerships also employ people with lived experience in paid roles such as peers mentors and navigators. Our focus in this report is generally on the contribution experts make to systems change in a voluntary capacity.
3. As illustrated by the growth of the What Works Network, for example. [www.gov.uk/guidance/what-works-network](http://www.gov.uk/guidance/what-works-network)
4. Navigators are service-neutral staff members who build trusting relationships with people affected by multiple disadvantage and support them to engage with a range of support and services as needed.

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