Systems change for people experiencing multiple disadvantage

What have we learned about the system and how it can change?

Fulfilling Lives LSL Research and Learning Partnership

NPC, Groundswell, and CRESR

March 2022

FULFILLING LIVES
LAMBETH
SOUTHWARK
LEWISHAM

COMMUNITY FUND

NPC

Groundswell
Out of homelessness

Sheffield Hallam University | Centre for Regional Economic and Social Research

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Executive summary

This report synthesises the findings of two years of research and learning with Fulfilling Lives Lambeth, Southwark, and Lewisham (LSL).

Fulfilling Lives LSL is part of a national programme testing new ways of supporting people experiencing multiple disadvantage, so that individuals are better able to manage their own lives. It is funded by The National Lottery Community Fund.

Fulfilling Lives LSL contracted NPC, Groundswell, and The Centre for Regional Economic and Social Research at Sheffield Hallam University as research and learning partners. The partnership sought to build an understanding of the current system of support in Lambeth, Southwark, and Lewisham, explore how it could change, and share that learning across the system. These lessons are crucial to helping services, commissioners and other stakeholders work together to support individuals more effectively—ultimately helping more people to lead more fulfilling lives.

Throughout this report we link to other resources produced by the partnership, where you can learn more about the research and its findings.

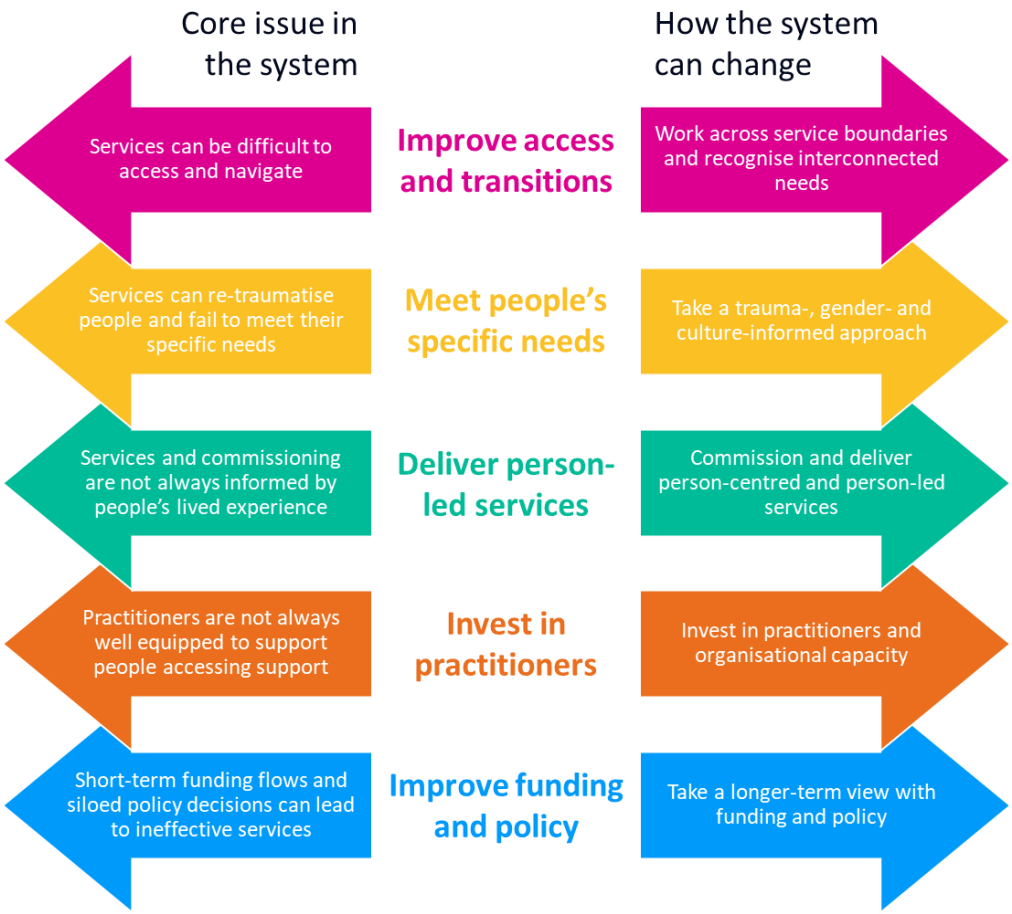
The research identified five core issues in the system, alongside recommendations for how each can be addressed:

1. **Services can be difficult to access and navigate.** This could be due to a lack of accessible information about services, rigid eligibility criteria, or logistical barriers. The research highlighted the importance of collaboration between services and across traditional boundaries to help people experiencing multiple disadvantage access the right services to support them.
2. **Services can re-traumatise people and fail to meet their specific needs.** People experiencing multiple disadvantage may need to re-tell stories of previous trauma as they transition between services, which can be re-traumatising and demoralising. In addition, universal services are not always equipped to support the needs and priorities of specific groups of people, such as women or people from minoritised communities. The research highlighted the need for services to take a trauma-, gender- and culture-informed approach.
3. **Services and commissioning are not always informed by people's lived experience.** Support services are often designed rigidly, where someone is expected to make linear progress to

'overcome' a particular issue. This does not reflect the reality of relapse and recovery for most people. Our research found there is a need for person-led and person-centred services that better match the realities of people's lives and their goals.

4. **Practitioners are not always equipped to support people accessing services.** Service providers and practitioners often have limited resources, which makes it hard for them to develop tailored support or take time to develop their practice. Our research suggests that investing in practitioners and organisational capacity has the potential to transform the system for people experiencing multiple disadvantage, by enabling practitioners to provide longer-term, high-quality, person-led and person-centred services.
5. **Short-term funding flows and siloed policy decisions can lead to ineffective services.** Short-term funding creates instability for many service providers, who are often not able to offer staff longer-term contracts or offer people accessing services a guarantee that the service will still be there in the future. Siloes between services can mean that individuals receive inconsistent and unconnected support, which does not meet their needs. The research found the need for policymakers and commissioners to take a longer-term and more holistic view, to enable services to provide joined-up support which works for individuals.

Figure 1: Summary of core issues and how the system can change



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Introduction

2.1 About this report

This report by the Fulfilling Lives Lambeth, Southwark, and Lewisham (LSL) Research and Learning Partnership summarises what we've learnt from two years of research, and brings together the other resources we have produced. These include:

- *Understanding Models of Support for People Facing Multiple Disadvantage: A Literature Review* (September 2020)
- *Trauma-informed approaches: What they are and how to introduce them* (October 2020)
- *Dealing with trauma and trauma-informed care* (October 2020)
- *Gender and culture-informed approaches: What they are and how to introduce them* (October 2020)
- *Systems mapping multiple disadvantage* (March 2021)
- *People's experiences of multiple disadvantage in Lambeth, Southwark and Lewisham: A peer research project* (June 2021)
- *Groundswell, The Missing Piece podcast* (June 2021)
- *Groundswell, Listen to me! podcast* (July 2021)
- *Re-thinking Outcomes: A practical guide for services designed for people experiencing multiple disadvantage* (December 2021)
- *Re-thinking Outcomes: A guide for commissioners of services designed for people experiencing multiple disadvantage* (December 2021)

Throughout this report, we refer to further reading about the issues covered in each section. This includes links to Fulfilling Lives LSL publications and other relevant partnership outputs, all of which can be found on the Fulfilling Lives LSL website.

2.2 Who is this report for?

This report will be useful to several different groups:

- Service providers, commissioners, funders and policymakers involved in supporting people experiencing multiple disadvantage. This includes people involved in areas such as: mental and physical health; substance use; criminal justice; violence against women and girls; or services aimed at people who are sleeping on the streets.
- Academics and researchers seeking to understand what works to improve the lives of people experiencing multiple disadvantage.
- People experiencing multiple disadvantage, who can use this report as evidence for change.
- Campaigners and anyone else wanting to influence systems change for people experiencing multiple disadvantage.

2.3 The Programme

Fulfilling Lives Lambeth Southwark, and Lewisham (LSL) is one of 12 Fulfilling Lives programmes funded by The National Lottery Community Fund to improve the lives of people experiencing multiple disadvantage. We use the term multiple disadvantage to refer to people's interconnecting needs and experiences, including mental ill-health, homelessness, substance use, and interactions with the criminal justice system.

The programme works across three areas:

- **Co-production**: developing a culture in which people experiencing multiple disadvantage are at the heart of designing and delivering services.
- **Service delivery**: testing and learning about different interventions and models of service delivery alongside people experiencing multiple disadvantage.
- **System change**: providing an evidence-base to influence the way systems work at local and national levels, so as to create sustainable, long-term change for people experiencing multiple disadvantage.

More information is available on the Fulfilling Lives LSL website.

2.4 The Research and Learning Partnership

Fulfilling Lives LSL commissioned a two-year Research and Learning Partnership in March 2020. The partnership includes:

- Fulfilling Lives LSL
- NPC (New Philanthropy Capital)
- Groundswell

- The Centre for Regional Economic and Social Research (CRESR) at Sheffield Hallam University

Our research has drawn upon the experiences of those involved in commissioning, managing, and delivering services and the views of people with experience of multiple disadvantage. The partnership has three aims:

- To understand local systems.
- To understand the barriers and challenges that people experiencing multiple disadvantage experience when accessing services.
- To identify points in service systems where interventions could make significant differences to service access and/or transitions.

2.5 Definitions

People experiencing multiple disadvantage

People experiencing multiple disadvantage have interconnecting needs and experiences, including mental ill-health, homelessness, substance use, and interactions with the criminal justice system. Whilst we use this language throughout our research, we also recognise the need to look beyond labels and challenge stereotypes:

> *"Terminology and labels are, of course, useful in helping to address and highlight issues people face, but… it is important for us to look beyond labels and at the people behind them. The language we use is important and powerful; it can challenge or reinforce stereotypes around multiple disadvantage." (Peer research report)*

People accessing support

In this research, 'people accessing support' refers to people experiencing multiple disadvantage who are accessing support in Lambeth, Southwark, and Lewisham. They have contributed their perspectives to our research from their experience of accessing services and what helped or hindered them on their recovery journeys.

System

A 'system' is a set of things interconnected in such a way that they produce their own patterns of behaviour over time. These include tangible things like people, resources, and services, but also intangible things like relationships, values, perceptions, and power dynamics.[1]

[1] Read more in NPC (2015) *Systems change: A guide to what it is and how to do it*

The system we are interested in is made up of all the factors that influence the support options available to people experiencing multiple disadvantage within Lambeth, Southwark, and Lewisham, and everything that affects people's experience of this support.

Systems mapping

Systems mapping is a tool to help stakeholders better see and understand their system and its behaviours. It provides a visual representation of the different parts of the system, the connections between them and their causal relationships. This focuses attention on how the system behaves: the relationships, structures, power dynamics and mindsets that together drive the way that people in the system act.

We used systems mapping to better understand the support system for people experiencing multiple disadvantage in Lambeth, Southwark, and Lewisham. This understanding can help policymakers, commissioners, services and practitioners change policy, design new interventions, and change ways of working to shift the system and more effectively address the complex web of causes that contribute to an issue.

People working in the system

Many of the quotations used in this report are attributed to 'people working in the system'. These people include practitioners, service managers, commissioners, policymakers, and decision makers. The views in this report represent the perspectives or experiences of people in the system who took part in our research. This might not be representative of everyone's experience and some nuance will inevitably be lost in the process of mapping a complex system.

As is typical in a complex system, many people working within it feel frustrated or powerless to change things on their own. Problems highlighted in our research are not intended as criticism of individuals, but of the system itself. People working in the system are also well-placed to highlight good practice or innovations that point to how the system can change for the better.

We are grateful to all the people with lived experience and people working in the system in Lambeth, Southwark, and Lewisham who participated in our research. Your insights, passion and commitment are at the heart of this report. We hope that this research will be a step towards ensuring that people experiencing multiple disadvantage are able to access the support they need.

3

Methodology

Our research had two main phases:

1) Understanding the current support system for people experiencing multiple disadvantage in Lambeth, Southwark, and Lewisham.
2) Exploring how that system can change.

We provide details on each of these phases below, along with a summary of our main findings.

3.1 Understanding the current system (September 2020 to June 2021)

Our research built up an understanding of the support system that people experiencing multiple disadvantage can draw upon in Lambeth, Southwark, and Lewisham. We looked at what was happening, how it was happening, and why it was or was not working for people. Our findings are informed by a variety of research methods including a literature review, systems mapping, and peer research.

Literature review

CRESR reviewed the existing literature on models of support for people experiencing multiple disadvantage and published their findings. Their literature review focused on work carried out within the UK relating to adults and which was published within the last 15 years. They reviewed academic literature; policy documents; research sponsored by the UK, local and devolved governments, charities and service providers; evaluations of policies and programmes; and 'grey literature'.[2] CRESR identified relevant literature through an IDOX Information Services enquiry and database searches using key search terms.

[2] Grey literature refers to materials or research produced by organisations outside traditional commercial or academic publishing and distribution channels. This can include research reports, policy documents, working papers, conference proceedings, blogs, podcasts, and social media posts.

Systems mapping

NPC led on mapping how the system works (or does not work) with input from the other research partners. First, the research partners conducted interviews and workshops with people with lived experience of accessing support and with the Fulfilling Lives LSL team to understand their experience of services across Lambeth, Southwark, and Lewisham and the barriers to accessing those services. We then held a series of workshops with practitioners, service providers and decision makers across the three boroughs, as well as a workshop with people with lived experience of accessing support, to increase our range of perspectives and identify where we needed to explore more. We sought to understand the underlying drivers behind the system behaviours we identified.

Peer research

Groundswell conducted peer research to gather insights from people with experience of multiple disadvantage. The peer research was co-designed and delivered with input from researchers with experience of multiple disadvantage—both Groundswell team members and experts by experience.[3]

Five experts by experience were recruited to participate in the entirety of the process including designing research questions; helping to recruit participants; designing consent forms and information sheets; feeding back on case studies; reflective writing and drawing; thematic analysis of interviews, writing the report, and recording a podcast.

The research included 41 telephone interviews with people either living in or receiving support from services in Lambeth, Southwark, and Lewisham, as well as an online survey.

Analysing findings

We brought our findings together across the research partnership to develop a shared understanding of the issues in the current system for people experiencing multiple disadvantage in Lambeth, Southwark, and Lewisham. Two points are worth noting about the scope and nature of our findings:

- Whilst our primary research focused on Lambeth, Southwark, and Lewisham, many of our findings related to the system more widely. For example, our conversations with local stakeholders about the importance of responding to the trauma people had experienced were echoed by the literature review which sets out the rich academic evidence base on this topic across the UK. Similarly, our system mapping workshops identified root causes of local issues which related to national policy decisions, funding flows, relationships, power dynamics and mental models.
- The system was in flux during the period in which we carried out this phase of research. Covid-19 disrupted established ways of working and

[3] After a discussion about how they would like to be referred to, the volunteers decided they would like to be referred to as 'experts by experience'.

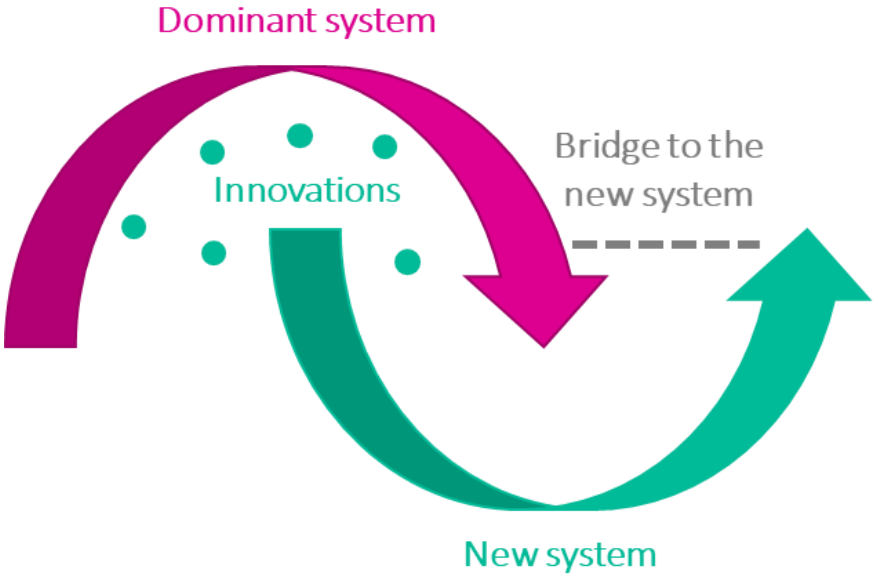
caused many services to reconsider how to provide effective support. The pandemic response demonstrated that the system can adapt quickly to meet an unmet and unknown need both at an individual, community and organisational level. Nonetheless, many questions remain about how this crisis response can be sustained. It is clear from our research that we need longer-term change if the system is to work better for people experiencing multiple disadvantage.

3.2 Exploring how the system can change (July to November 2021)

Building on the shared understanding of the issues in the current system for people experiencing multiple disadvantage in Lambeth, Southwark, and Lewisham, our research changed focus to explore how this system can change. We explored places in the system where small changes could have a great impact.

We also looked at innovations or good practice in the current system that could be replicated or scaled up, including examples from Lambeth, Southwark, and Lewisham, as well as from further afield. As shown in the diagram below—inspired by the Berkana Institute's two loop model—innovations play a key role in building a new system. Illuminating and nourishing these innovations helps them to spread and to challenge the dominant system.

Figure 2: Two loops model



Source: adapted from Margaret Wheatley (2002)

Again, our findings for this phase are informed by a range of research methods. Building on our previous work, the partnership:

- identified examples of positive interventions from around the UK in the existing literature on support models for people experiencing multiple disadvantage;
- gathered insights from people with experience of multiple disadvantage in Lambeth, Southwark, and Lewisham about what helped them on their journeys, through peer research; and
- explored places where the system can change through interviews and workshops with service providers, commissioners, decision makers, and people with experience of accessing support in the three boroughs.

As with our research about current issues, the system was in flux during the period in which we carried out this phase of research. Covid-19 led to some innovations in how services are delivered, some of which benefited people accessing services. These innovations still sit within a wider 'dominant system' that often works against them—for example in the way funding is channelled. It remains to be seen how sustainable these innovations will be as the system seeks to revert to its 'normal' state.

As part of this phase, we identified a particular need for guidance on re-thinking outcomes to support the delivery and commissioning of person-centred and person-led services. This issue came up multiple times in our research and was felt by many stakeholders to be a key sticking point for improving services. In response, the research partnership developed guides for service providers and commissioners on re-thinking outcomes for person-centred and person-led services.

3.3 Bringing together our findings (December 2021 to January 2022)

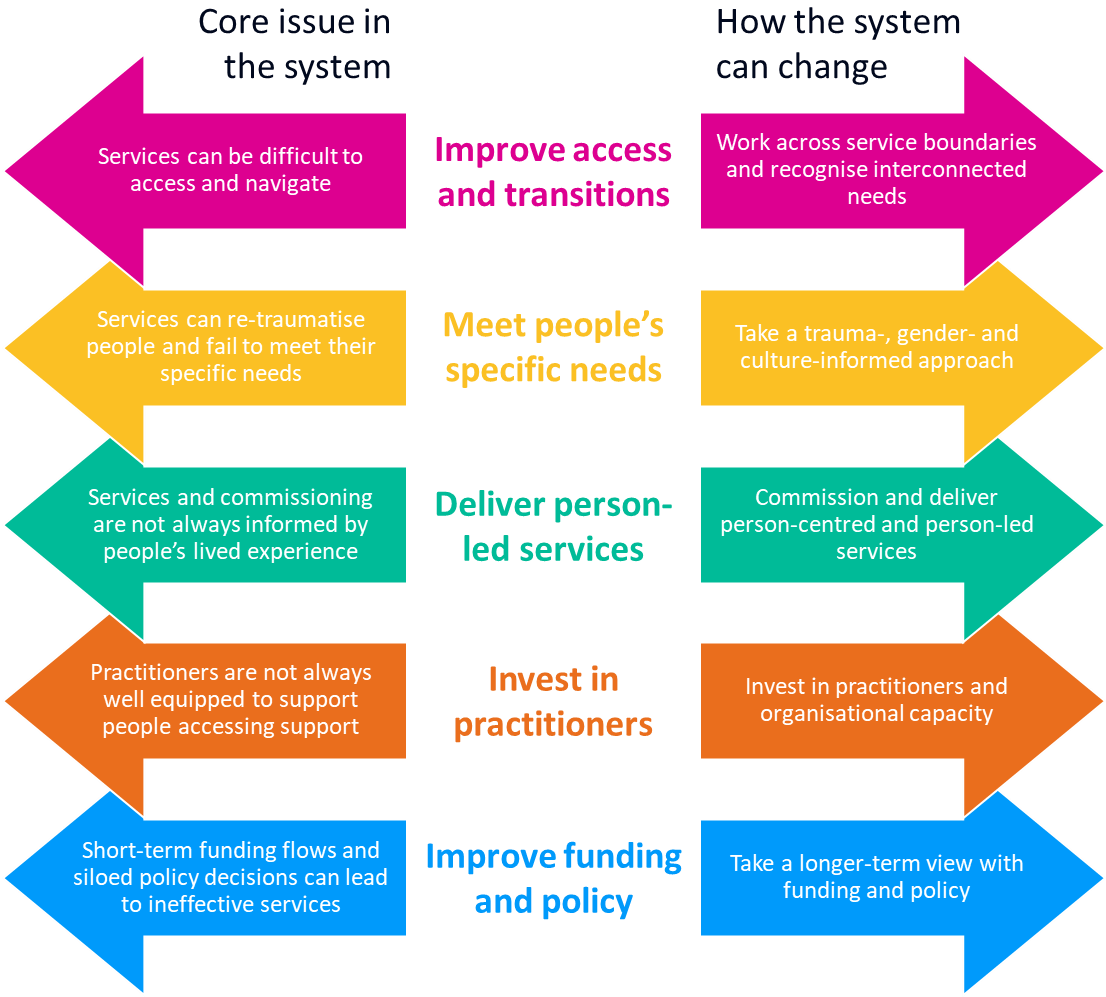
Throughout our research, we heard from people about a range of issues with the current system and ideas for how it could change for the better. Our findings encompassed many levels of the system: from people's experience of services; through to the behaviours and incentives for practitioners, service providers and commissioners; and the funding flows and policy decisions that shape the way the whole system works. We also heard that the existing system is held in place by more intangible things such as power dynamics between practitioners and people accessing services, relationships between service providers and commissioners, and stigma surrounding issues like mental ill-health and substance use.

Changing the system for the better is no easy task. It demands that we overcome deeply entrenched structures, behaviours and beliefs that hold the existing system in place. Nonetheless we heard many reasons to be hopeful. Within the existing system, there are many people working tirelessly to try new approaches and to improve the things that they can influence. If nurtured, these innovations have the potential to build a new system that works better for people experiencing multiple disadvantage. We hope that this report helps to illuminate the ways in which the system is already changing as well as highlighting ongoing challenges.

We have synthesised our findings into five core issues and five principles for how the system can change, and we've organised these around five themes. These are shown in Figure 3 below.

Each of the next five chapters takes one theme and summarises our findings about the core issue and how the system can change. The themes are of course inter-related, so change in one area will be influenced by change (or lack of change) in another area. We need change in all five areas to improve outcomes for people experiencing multiple disadvantage over the long term.

Figure 3: Summary of core issues and how the system can change



4

Improve access and transitions

4.1 Core issue: services can be difficult to access and navigate

The Fulfilling Lives LSL programme is based on a belief that *"no person is hard to reach but systems can be hard to access"*. Our research identified multiple barriers to people accessing and navigating services.

The first challenge is finding services. Information about different services, eligibility criteria, and how to access them is not always readily available or accessible. A lack of clear information about the options available can increase the stigma or fear that people feel about accessing services. For example, parents may choose not to get help from social care services as they fear it would lead to involvement from child protection services.

Finding services is not the only challenge to accessing support. Once a service has been identified, it may have rigid processes and access criteria. In the worst case, people may be excluded altogether. For example, some people with 'no recourse to public funds' (NRPF) due to their immigration status were denied temporary accommodation following the support they received from the 'Everyone In' scheme. More commonly, people report their experiences of having to 'jump through hoops' or 'tick a box' to access services. For example, a person going through a relationship breakdown but whose name is still on a tenancy agreement may not be able to access homelessness support. These kinds of conditions can hinder people's ability to get the support they need.

"They've got a book and if you don't fit into it they don't see this." (Person accessing support)

There are also practical and logistical barriers to accessing services for people experiencing multiple disadvantage. Having to remember appointments, waiting long periods between appointments, or not being able to attend outside 9-5 hours can be significant barriers for people experiencing mental ill health, substance use and homelessness. During the pandemic, many services moved away from face-to-face contact towards telephone and internet services only. This made it harder for those who don't have the technology or skills to access online appointments.

Universal services[4] may have a poor understanding of the challenges that people experiencing multiple disadvantage face when trying to access their support. Services may assume that people are choosing not to engage due to a lack of motivation or apply damaging labels to people such as 'hard to reach' or 'non-engager', which in turn may affect people's access to future support.

"We believe no person is hard to reach but systems can be hard to access." (Fulfilling Lives LSL)

Once people begin to engage with services, many find them difficult to navigate. Poor coordination between different services can prevent people getting the help they need. Barriers to information sharing can mean practitioners are not always aware who else is supporting a person, which prevents coordinated plans and positive referrals to appropriate services.

"Ultimately services don't, you know, work together, you know, mental health teams do not speak to homeless teams and homeless teams do not speak to other departments." (Person accessing support)

Many services are designed to focus on one need at a time, but people experiencing multiple disadvantage may need to access different kinds of support at once. Strict access criteria may require people to 'deal with' one need before another, leaving them unable to have their needs met.

Notably, people with a dual diagnosis of mental ill health and substance use often find themselves being passed between two services. Mental health support may not be available until a person has 'recovered' from their drug addiction. Similarly, a person may be unable to access support for substance use while experiencing mental ill-health. This inflexible approach can leave people completely stuck and without support altogether.

"Whenever we try and request a mental health assessment, so as people can get the right support, they will often say... they need to cut down on their drug use first. And you just think, well they are using the drugs to manage their mental health. And it's kind of a difficult one – which came first, the chicken or the egg. But we do find a lot is no mental health services will touch you until you stabilise… or cut down on your drug or alcohol use." (Person working in the system)

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[4] Universal services are those which provide support to anyone presenting with a specific need. They tend to be designed to cater to the needs of the majority.

Points of transition are particularly difficult to navigate, whether these are transitions between services or life transitions such as moving home. Evidence in the literature review highlights numerous examples of problematic assessment, support planning and provision in the context of transitions, which delayed people accessing the services they needed. For example, there can sometimes be gaps in support between probation officers and housing services, with prison leavers needing to reapply for services upon release.

Lack of coordination around transitions can leave people without support at crucial times or lead to delays in progressing through treatment. For example, people accessing mental health services may not always be supported to develop a discharge plan for when they leave the service or be able to see a psychiatrist to have a medication review before the end of their treatment course.

"And then by the time it does come round, your 12 weeks might be over, and you are being discharged. And you haven't had your review. And then you have got to start all over again." (Person accessing support)

People may worry about how they will cope without support and the loss of trusted relationships, whether from changing friendship groups or changing support workers. People may feel alone, causing these anxieties to grow. Limited preparation can create a challenge for people making significant transitions, such as people leaving care and those moving into and out of supported accommodation. Information about transitions may be difficult for people to access or understand, which can leave people with a 'fear of the unknown'.

In some cases, people can go back and forth in their journeys, which may undo the foundations that have previously been established. People may return to old patterns of behaviour, which feel 'safer' when met with a potential 'jump into the unknown'.

Read more:

- Systems map: 'Barriers around accessing support', 'Barriers around engaging support' and 'Barriers around transitions between and from services' sections
- Literature review: Chapter 2
- Peer research report: Chapter 3

4.2 How the system can change: work across service boundaries and recognise interconnected needs

Our research highlights the need for greater collaboration between services and across traditional boundaries to meet the needs of people experiencing

multiple disadvantage. When service providers and practitioners can see the whole person, they can better understand that person's context and how the challenges they experience are connected. This impacts the relationships that are built and the quality of the support they can give—particularly at points of transition in people's lives. This in turn affects the wellbeing and recovery of people experiencing multiple disadvantage.

"it is vital that professionals working in these fields recognise that they are very often working with the same people viewed through different 'lenses'" (Literature review)

Some services recognise and respond to multiple needs. This was seen as highly beneficial by many people experiencing multiple disadvantage. One example given was The Harbour, a drug and alcohol support service in Lambeth for people wanting to sustain their recovery.

"I am due to go there [The Harbour] tomorrow actually for two appointments funnily enough. One in the morning to do a [substance use] group and then one in the afternoon to get housing support." (Person accessing support)

Another example is The Beth Centre, a safe confidential space providing expert support for women at risk of, or affected by, the criminal justice system living in Lambeth. It aims to reduce contact with the criminal justice system; increase positive family relationships and increase the use of community sentences, rather than custody, for women. The Beth Centre's key workers coordinate support across a range of interconnected issues.

"[T]he Beth Centre, they are really good, because it's all for women who have been in contact with the criminal justice system. They are actually run by women in prison and they have got a worker there to cover everything. So, they have got a worker who works with substance misuse. They have got a mental health worker in there. They have got another worker who deals with domestic violence. So, they work collectively with each other. So, you can go in there with all your different issues and collectively they will work with you. You have a key worker, but collectively they will work with you." (Person accessing support)

However, research participants recognised that some services can often only offer support for one issue, due to the ways that services are designed and commissioned to focus on a specific issue like homelessness. In this instance, collaboration between services can lead to joined-up support that meets the needs of people experiencing multiple disadvantage.

Collaboration between services is helped by personal relationships and physical proximity, so that services are aware what other services support the people they work with. For example, services being co-located in the same buildings can help collaboration, as can services going to places where people already are.

"The Fulfilling Lives team popping into the women's hub leads to a rippled-out effect. People feel like they have an additional home, another place where they feel comfortable in the community." (Person working in the system)

Multi-agency meetings are another opportunity for different services to work together to support people experiencing multiple challenges. They enable staff working in different services to build relationships and build up their knowledge of the network of services in the area. However, there is a danger that such multi-agency meetings may only happen when a person has reached crisis point, rather than services working together from the start to stop issues escalating. Leadership from individual practitioners such as link workers can make multi-agency working more proactive and effective (see Jo-Jo's experience below).

Case Study: Jo-Jo – working across services

Jo-Jo was trafficked to England at the age of 18 and sexually exploited through the sex trade. She has no family or support network in the UK. She is experiencing domestic violence, sexual exploitation, addiction and mental ill health linked to trauma. She became homeless after fleeing a domestically violent relationship. Jo-Jo was referred to the FLLSL programme and has worked with her link worker for two years.

Jo-Jo's link worker referred her to the Multi Agency Risk Assessment Conference (MARAC) to ensure that all the services which attend the panel and the police were aware of Jo-Jo's situation and the level of risk involved. It was also important to ensure that services in both London boroughs where Jo-Jo resided were communicating regularly to safeguard her and to locate her when she went missing. Jo-Jo was supported by seven different services including substance use services, domestic violence advocacy, a specialist HIV clinic, housing, GP and charities. Jo-Jo's link worker describes the benefits of working with other services:

"I think the good thing about all of the services that Jo-Jo was linked in to is that we all worked incredibly flexibly, which is definitely what you needed whilst working with her. Because unfortunately sometimes she would go MIA [missing in action]. So, she would just completely drop off the radar, completely disengage. And it would just be really difficult to try and find her. So, we would do a lot of home visits, a lot of door knocks."

Read Jo-Jo's fully story in the peer research report, page 27.

There is a need to build structures that ensure services continually work across disciplinary boundaries. The system shouldn't have to rely on individual practitioners such as link workers to make collaboration work. For example, multi-disciplinary meetings and collaboration should be outputs in and of themselves and should be embedded into tender agreements when support services are commissioned to address needs like mental ill-health or substance use. This would ensure that these services collaborate and work towards addressing co-existing issues that the people they support might experience.

Similarly, providing spaces for joint working and shared learning can transform services for people experiencing multiple disadvantage. For example, Fulfilling Lives LSL has established a shared learning forum to support shared learning and communication between local services working with women experiencing dual diagnosis and multiple disadvantages compounded by exploitation. Commissioners and service providers regularly come together to share their experiences and what they've learnt from this group and what works best in delivering services for them.

Joined-up thinking at the commissioning and policy levels could drive more collaboration between services. For example, local boroughs could develop a joint strategic needs assessment (JSNA) on multiple disadvantage, which they could use to inform strategic commitments across the borough. Local areas could also use joint commissioning models to improve pathways of care for people experiencing multiple issues. Commissioners should commission services specifically focused to address 'dual diagnosis' and ensure that services addressing mental ill-health and substance use are accessible and equipped to support people who have co-existing needs.

Commissioners should consider transition points, when support is often most needed, but often absent. Such support is more effective when trusting relationships are developed between services, practitioners and the people they support. In addition, services that have low or no criteria for entry play an important role in preventing crisis situations.

Read more:

- Systems map: 'Barriers around information sharing and collaboration' section
- Literature review: Chapter 2
- Peer research report: Chapter 3

5

Meet people's specific needs

5.1 Core issue: services can re-traumatise people and fail to meet their specific needs

The majority of people experiencing multiple disadvantage as adults experienced trauma as children. However, services are not always equipped to recognise and respond to people's trauma and its continuing impact.

> *"Because I do feel like my trauma… childhood issues, rape, bereavement – I think all these things add to why I... I am in and out of recovery. In terms of my substance misuse." (Person accessing support)*

People experiencing multiple disadvantage can find they need to continually re-tell their story as they transition between services, which can be re-traumatising and demoralising. Siloed working and poor information sharing mean that relevant information is often not passed between services.

> *"It's a bit of a headache – you have to explain the same thing to one person and another place – and if they're not linked you have to do the double work." (Person accessing support)*

This is further compounded when people are not able to be seen by the same practitioner consistently due to staff turnover or practitioners having to support high numbers of people.

> *"I went through a long period where I was passed from one worker to another. Constantly having to restart a relationship and go through traumatic memories. The new workers just picked up the info the previous worker left, and*

made their own mind up from that." (Person accessing support)

Continually re-telling your story contributes to a wider feeling of not being listened to, understood, or adequately supported by services.

"You might feel worse from engaging with services. You're not going to get better because of the way you get treated. But you have to engage with the system to get better and get support." (Person accessing support)

Some services may not be sympathetic to the effects of trauma on people's lives and therefore may not be responsive to behaviour triggered by trauma. Services may exclude people for their perceived 'poor' behaviours including frustration, anger, shouting and swearing, without appreciating why people have these reactions. This can continue to build up over time for people experiencing multiple challenges and needing to access several services.

"We are talking about services that... aren't flexible enough. You know, you miss an appointment, that's it, you can't come back in. They don't understand the behaviours that come with trauma, they don't understand why people might get anxious or aggressive or the whole fight, flight, flee and stuff. Their reaction to trauma, they don't understand that so they… it's kind of what is wrong with these people rather than what's happened to them?" (Person working in the system)

Universal services are not always equipped to support the needs and priorities of specific groups of people experiencing multiple disadvantage, such as women or people from minoritised communities. This leads to inadequate support, particularly for those with the highest need. People's specific needs are influenced by their experiences and the intersections of their identity, such as their gender, ethnicity, and cultural context, which may not be met by universal services. For example:

- **Gender:** Many generic services supporting people experiencing multiple disadvantage are intended to be gender neutral and fail to consider the specific needs women or men may have related to gender. They may not understand the potential effects on women of having suffered gendered violence and abuse and may show a lack of empathy, for example by 'victim-blaming'. In cases where women are primary caregivers they may feel unable to access support due to practical concerns such as childcare and the timings of services, or may experience guilt due to societal expectations of women as

'homemakers'. Societal expectations can also influence men's access to services, with men less likely to access services explicitly referring to 'mental health' for example. (See literature review section 3.3)

- **Ethnicity and cultural context:** People's ethnicity and cultural context can significantly impact their experiences of trauma, as well as their experiences of services and the system. For example, experiences of racist discrimination can contribute to trauma and mental ill-health among people from ethnic minority backgrounds. Mainstream services are often not designed around the needs of people from minoritised communities and specialist services are underfunded. The disparity between people's needs and the services available to them is reflected in the impact of support on different groups. For example, due to a lack of access to culturally appropriate therapy, generic mental health services do not tend to deliver the same positive impact for Black people when compared with their White counterparts. Stigma around challenges such as addiction occurs in all communities and can put people off seeking support; but this stigma may show itself in different ways in different communities and this is not always well-understood by service providers. Similarly, people's needs might remain hidden and unmet because of service providers' assumptions about cultural norms. For instance, services may wrongly assume that the Muslim women they support do not have experience of substance use. (See literature review section 3.2)
- **Disability:** People with disabilities experiencing multiple disadvantage may experience additional barriers to accessing services. For example, not all services are accessible to people who use wheelchairs and there is a lack of suitable ground floor accommodation in many areas. (See literature review section 2.4)
- **Sexuality:** Rates of abuse for LGBT+ people appear to be higher than the heterosexual population and they are vulnerable to homo/bi/trans-phobic abuse. LGBT+ people may fear talking to services if it means they must 'come out' to them as well as discussing their other needs. (See literature review section 2.4)
- **Age:** Limited availability of services for different age groups can lead young people to access services alongside adults. This can mean that their needs are not fully understood or met. It might also present additional risks for young people, such as being groomed or influenced by others.

Limited resources in the system often lead commissioners to prioritise universal services that can deliver support to large numbers of people. As a result, people from across the spectrum of needs are sometimes grouped together when accessing support, in services that are not able to tailor support to people's specific needs and are not typically intersectional. All of this means that some people fall through the gaps altogether or can only access services that don't meet their needs.

"Not a single woman we support isn't impacted by multiple areas and systems. Our service tries to support them in a holistic way but this isn't replicated elsewhere." (Person working in the system)

Read more:

- Systems map: 'Barriers resulting from the way services are set up' and 'Barriers around knowledge, attitudes and emotions' sections
- Literature review: Chapters 2, 3 and 4
- Peer research report: Chapter 3

5.2 How the system can change: take a trauma-, gender- and culture-informed approach

The most effective services recognise that people's needs are influenced by their experiences and the intersections of their identity, such as their gender, ethnicity and cultural context, and any experience of trauma. In particular:

- **Trauma-informed approaches** recognise specific needs that people may have as a result of past or ongoing trauma.
- **Gender- and culture-informed approaches** recognise how people's specific needs are influenced by their gender, their cultural background, or both.

Trauma-informed approaches

It is difficult to define trauma-informed care. Providers whose services are described as 'trauma-informed' have different views about exactly what it entails. That said, the academic literature suggests some consistent principles which often underpin trauma-informed approaches. These principles do not define trauma-informed care, but they do help us to understand what it looks like. Our guide to trauma-informed approaches sets out five principles for providing care in a trauma-informed way:

1. **Recognise and respond to trauma.**

   For example: think about how to avoid people having to continually repeat their life story. Collect only the most needed information and manage it transparently with people accessing support. Avoid repeated and unnecessary questions, which could be distressing.

2. **Provide safe environments.**

   For example: service providers can help foster safe environments by putting collaboration, choice and empowerment for people at the heart of services. This means making people aware of the choices they have over their care, and supporting them to make informed choices.

3. **Take a strengths-based view.**

   For example: build on what people are capable of doing, rather than 'doing things for them'. Don't ask people 'what is wrong with you?' – instead ask 'what happened to you?'. Understand the connection between someone's experiences and their strengths and challenges.

4. **Build empowering relationships.**

   For example: give people a say over how services are delivered, and focus on building respectful, compassionate, and trusting relationships, so that people accessing support are not in a position of powerlessness.

5. **Promote equality of access.**

   For example: recognise the needs of the individual and ensure that everyone has equal access to good quality treatment which takes account of the unique context of their life. Do not exclude specific people because of things that have happened to them.

Trauma-informed approaches can be empowering for people accessing services, supporting them to feel in control during their recovery journey. As a result of understanding more about trauma, peer research participants spoke of how they learnt ways to communicate what they needed.

"I might need to explain some of the trauma and then retraumatise myself. But I've now since learnt that I'm actually able to say, 'It's too traumatic for me to talk about it, I can't talk about it. There is a letter from my doctor in my notes, read that.'" (Person accessing support)

Gender- and culture-informed approaches

There is significant overlap between gender- and culture-informed support. Both promote a wider understanding of people and their experiences, so we can respond holistically. Both require building trusting relationships to understand people's specific needs and preferences. Both are intimately linked to trauma-informed care, building on many of the same principles.

Gender-informed approaches acknowledge and respond to how gendered social norms and structural inequalities shape people's experiences and their specific needs.[5] Research by the charities AVA and Agenda (who tackle violence against women and girls) suggests that an ethos which prioritises understanding the reality of women's needs and lives is fundamental to delivering gender-responsive services. This can be embedded structurally, for example through the 'Mapping the Maze' framework.

[5] Much of the recent academic research on the role of gender in support services focuses on the distinct experiences of women. This is likely a reaction to the historic failure of research to recognise that women's needs can differ from other genders. As a result, many of the findings we share here also focus on women, rather than on men or people who identify outside the gender binary.

Case Study: Mapping the Maze

Mapping the Maze is a good practice framework for commissioning and delivering services to meet the specific needs of women facing multiple disadvantage. It was developed by the charities AVA and Agenda, with support from the Barrow Cadbury Trust.

The framework has four main components:

1. An organisational commitment to delivering gender-responsive services and interventions

2. A safe, welcoming and enabling environment

3. A focus on how support is given just as much as on what services are offered

4. Organisational structures that enable gender-responsive interventions

Read the full case study in *Gender and culture-informed approaches*, pages 11-12.

Similarly, culture-informed approaches acknowledge and respond to how cultural norms and structural inequalities shape people's experiences and their specific needs from support services.[6] Unfortunately, there is relatively little literature on what constitutes best practice for culturally-informed services, beyond suggestions around displaying information in a range of languages and providing interpreters.

What research has been done suggests taking a holistic approach to the needs of the individual, and enabling people to receive support from those who have a shared understanding and experience of:

- Cultural norms.
- Being from a particular minoritised group.
- Memories and knowledge of a country of origin.
- Experience of racism or prejudice.

This could have implications for recruiting staff and volunteer teams. For example, 'brokerage' roles can help support people from minoritised communities to access services at a similar rate to the majority population. It could also change how services work with people they support, such as by embedding a culture of co-production whereby services are shaped by the lived experiences of people from different cultural backgrounds.

[6] Given the difficulties of defining particular cultures, academic research on the role of culture in support services tends to use characteristics such as ethnicity and religion as a proxy for culture. However, while someone's ethnicity or religion can influence their culture, they do not define it. Given the limitations in the literature, we have drawn on research which conflates ethnicity and/or religion with culture, but we recognise this is an imperfect approach.

Embedding informed approaches

A shift to trauma-, gender- and culture-informed approaches cannot be done piecemeal. We identified three guiding principles for service providers looking to embed these approaches in their work:

1. **Take a whole organisational approach:** Informed approaches have to apply to all aspects of your work and be underpinned by a 'culture of thoughtfulness' across your organisation. Committed and effective leadership is needed to sustain change. 'Champions' can help with the day-to-day delivery and act as role models for their colleagues. 'Leads' for specific groups or identities such as 'gender leads' can help to ensure their needs and priorities are embedded across the organisation.
2. **Provide staff training, support and supervision:** Teams should be trained to understand what providing informed care means, and why it is relevant to their work. For informed approaches to be effective and valuable, practitioners must want to work in this way because they believe it has value, not simply because policy obliges them to do so.
3. **Protect staff wellbeing:** Since informed approaches require practitioners to engage with people's traumatic experiences, it may cause them distress as well. Organisations therefore need to promote a culture that supports staff wellbeing. This includes careful supervision and debriefing, ensuring no-one's workload is overwhelming, and leadership which fosters a culture of learning, trust and reflection, so that practitioners can say when they are struggling to cope.

Read more:

- Literature review: Chapters 3-5
- Peer research report: Chapter 4
- Trauma-informed approaches: What they are and how to introduce them
- Dealing with trauma and trauma-informed care
- Gender- and culture-informed approaches: What they are and how to introduce them

6

Deliver person-led services

6.1 Core issue: services and commissioning are not always informed by the reality of people's lived experience

Services are developed based on policy and commissioning priorities, with limited opportunities for people with experience of multiple disadvantage to shape support. This can lead to a mismatch in expectations between those delivering and those accessing support.

Many support services are designed in a rigid way where someone is supported to 'overcome' a particular need within a pre-specified timeframe. After that support is finished, they are expected to be in a 'better place' and move on and not face any subsequent challenges. However, the reality for many people is quite different.

> *"I did a first community detox in 2017, and when I finished that community detox, I didn't feel that there had been much of an aftercare package… I didn't have any support after that, and then that's when it kind of spiralled out of control again." (Person accessing support)*

People with experience of multiple disadvantage explained that *"relapse is part of recovery"* and *"people should not be punished if that happens"*.[7] Research participants felt that support services, and the professionals working in them, need to understand and adapt to the bumpy road people experience on their recovery journey. What often happens is that services set out an inflexible pathway, which does not recognise the realities of relapse. For example, services often assume that people should have 'recovered' after a particular period of receiving support. If that person needs further support, there is often little available and the person may need to go back to the beginning to maintain their wellbeing.

[7] By 'relapse' we do not just mean addiction, but any challenge that means people feel that they have taken some steps back from where they want to be.

"Once I finish with services it doesn't necessarily seem that straightforward to be able to reconnect if I feel like I need further support. […] It's not as straightforward or as simple as you would imagine. And it's kind of like the only time I could reconnect with a service is if I end up really ill again." (Person accessing support)

Similarly, services are often designed to meet a pre-determined set of outcomes, based on commissioners' targets. Commissioners tend to prefer 'hard' outcomes such as improved health, employment and housing as these are seen as more straightforward to measure. However, 'soft' outcomes such as improvements in confidence or quality of relationships might be just as important to the person accessing support and may represent vital building blocks for progress in their journey. Also, services can be conditional and people's access to future support may be affected if they do not make the 'right' choices and meet the prescribed outcomes.

"If you fail to meet their requirements, then it can affect your relationship with them and the support you receive." (Person accessing support)

This prescriptive approach does not recognise people's agency, desires, or circumstances. For example, services may measure 'success' as a person giving up substances or leaving an abusive partner, even if the person actually wants to reduce their dependence or wants their relationship to continue but change. This mismatch can be damaging given the power dynamics between services and the people accessing support. The conditionality of services can contribute to a lack of trust between people accessing services and practitioners.

"When I was seeing the previous worker, I would get friends to go to the needle exchange because I knew that if that worker saw me at the needle exchange, I would be punished in some way. I was like I have got to get off it, I have got to get off it. And I would… get off it for a few months, you know. And then just… relapse, relapse, there was just this constant cycle." (Person accessing support)

Furthermore, the culture of 'doing to' people rather than 'doing with' people can make them feel patronised and not in control of their own treatment. This can hinder their recovery journey and damage their confidence in their own abilities.

"And there have been times when I felt really part of my treatment and then there has been other times when another experience, I have felt that decisions were being made for me that I didn't necessarily agree with but felt out of control to be able to do anything at the time. Been a bit of a mixed bag." (Person accessing support)

The mismatch between services and the reality of people's lives stems from the lack of involvement of people experiencing multiple disadvantage in shaping and designing support. Services often lack the resources and capacity to involve people in a meaningful way.

Practitioners may be expected to gather insights from people accessing services as well as supporting them with their needs, which is challenging when they are already supporting high numbers of people. In practice, this can become a secondary priority. Services don't always have the resources to carry out meaningful co-production, so they aren't able to build up convincing evidence that this approach works, which in turn prevents changes to commissioning upstream.

Meaningful involvement can also be undermined by prioritising expertise associated with professional qualifications over expertise arising from people's lived experiences.

"We've often located expertise with White people wearing lanyards… then we think why aren't people engaging with our services? Communities have valid and wonderful things to teach us about joy, wellbeing and recovery. We need to stop locating expertise with paid people and look at communities." (Person working in the system)

Even when people accessing support are involved in sharing and designing services, this is not always a positive experience – for example if people are not properly supported or reimbursed for their time. As one person told us: *"giving your time is draining".*

Not everyone accessing services will have the capacity to shape and design services. Some people may be dealing with significant personal challenges and may not be able to take part. Moreover, co-production can feel tokenistic, with people sharing their views and experiences but with limited change to the way services are delivered. This can be disheartening for those involved.

"It often becomes rigid and loses the flexibility because it has a fixed destination. They have already set parameters. It is supposed to be an adventure." (Person accessing support)

Social stigma also perpetuates the mismatch between services and the realities of people's lives. Limited awareness of the realities of the lives of people experiencing multiple disadvantage can lead to difficulties being seen as 'wrong lifestyle choices', rather than understood within the context of people's experiences.

> *"The housing was more important to me than heroin, but heroin was more available than housing, you know." (Person accessing support)*

A lack of understanding around these issues means people may feel blamed for the challenges they experience. For example, deep-seated beliefs about people who use substances can shape how services are run and designed. This stigma can lead to people feeling judged or misunderstood when accessing support and can hinder their wellbeing and recovery.

> *"I was in hospital last year with pneumonia and… Trying to get my methadone… I had to try and crawl out of the hospital because of the way I was being treated in here, it was awful. To have that label as drug user you know… Or kind of bottom of the pile, you know. And our issues are self-created…" (Person accessing support)*

Read more:

- Systems map: 'Barriers around engaging with support' and 'Barriers around shaping and designing support' sections
- Literature review: Chapter 2
- Peer research report: Chapter 4

6.2 How the system can change: commission and deliver person-centred and person-led services

Our research found there is a need for person-centred and person-led services that better match the realities of people's lives and their goals. The peer research found that listening to people, giving them choice, and supporting them to make their own decisions can have a transformative impact. Similarly, relationships can have a significant impact on the lives and wellbeing of people experiencing multiple disadvantage.

> *"I would say they have listened to me and that is why they have been able to help me and support me. I have come out of prison, they have come to see how I am doing, how my*

life is... They worked with me inside and they work with me out in the community" (Person accessing support)

Person-centred and person-led approaches differ from traditional approaches in several important ways, as shown in Table 1. Broadly speaking, **person-centred approaches** provide individualised support based on someone's needs, circumstances, and strengths. **Person-led approaches** also do this, and aim to give the individual greater power, control, and choice in their journey. In practice, services will often pivot between approaches, depending on a person's situation, needs, ability and desire to influence their support.

Table 1: Traditional, person-centred and person-led approaches: similarities and differences

Aspects	Traditional approach	Person-centred approach	Person-led approach
Support provided	Support based on what works for people with that 'issue'.	Individualised and coordinated support based on a person's need.	Co-created, individualised and coordinated support based on a person's wishes and aims.
Philosophy	Service is there for people to access, dependent on meeting a set of defined criteria.	Recognises the strengths and abilities of the person receiving support.	Recognises the strengths and abilities of the person receiving support. Prioritises the agency of the individual.
Value judgments	Service decides what is good for that person.	Services do not make value judgements about the choices people make and avoid using labels to describe people.	Services do not make value judgements about the choices people make and avoid using labels to describe people.
Time frames	Support is usually time-limited.	Recognises ups and downs in a person's journey. May be a time limit to support a person can receive.	Recognises ups and downs in a person's journey. Support is open-ended, based on a person's wishes.
Decision making	Services make ultimate decisions.	Joint decision making between the person receiving support and support services.	The person receiving support makes decisions based on their wishes.
Reporting	Outcomes determined by commissioners	Outcomes decided based on individual needs.	Outcomes determined in partnership between practitioner and

	and service providers.	person receiving support.

One of the main barriers to more person-centred and person-led services identified by our research is that desired outcomes are pre-determined by services and designed to meet commissioners' targets. Overcoming this requires service providers and commissioners to develop person-centred and person-led approaches to outcome measurement.

Such approaches recognise that people's journeys are not linear nor will they all experience the same outcomes. Where possible, outcomes should be determined in partnership with the person receiving support and based on their lived experience not the expectations of services or commissioners.

These outcomes frameworks need to recognise the importance of relational (or soft) outcomes such as improvements in confidence or quality of relationships, in addition to hard outcomes such as tangible changes in a person's housing, employment or health. Fulfilling Lives LSL has been working to identify how progress through its relational approach can be measured. It advocates outcomes being determined on an individual basis with practitioners noting the nuances in their observations of people.

Case Study: Fulfilling Lives LSL's Relational Service

FLLSL's community-based practitioners work alongside people to understand their needs and aspirations, and ensure they remain safe from immediate harm. This 'relational' approach offers consistent person-led support to develop trusted relationships, and then walks alongside people to navigate complex systems to receive the support they wish for.

A key question for the team has been how to measure the progress that people accessing the service make and what works. Progress on building trust and developing relationships was recognised by the team's practitioners in subtle ways, such as turning up to more encounters, being more open and sincere about their challenges. The team also recognised more fundamental behavioural changes in people such as getting in touch with the practitioner directly by phone to seek advice, and showing more willingness to consider things such as supported housing schemes, treatment programmes, and financial support.

While all of these can be measured (or recorded) in some way, the team explained too that everyone had a unique journey to go on and it was very difficult to assign a fixed set of measures to the service. In addition, such a relational approach required flexibility and freedom to respond to the situations, needs and wishes of each person. As such progress had to be judged on an individual, bespoke basis. What may be considered very small steps for one person, could be a huge stride by another.

"You know that you've got somewhere with somebody when it's you they pick up the phone to. And instead of them being out on their own, coping with whatever is happening in their life by themselves, they feel like they've got somebody they can pick the phone up to. And I think that that doesn't get measured."

Read the full case study in *Re-thinking Outcomes: A guide for commissioners*, page 13.

Co-production is also crucial in moving towards genuinely person-led services. Co-production means working together to find a solution, or to change or improve something—such as the way services are designed or commissioning decisions are made. Through giving equal value to the voices of both the decision makers and the people accessing support, co-production can ensure that services better reflect people's needs.

"We believe co-production is a way of working that is collaborative, shares power, and breaks down barriers between services/systems, professionals and the people who use services, creating a level playing field. It values the knowledge, skills, and contributions of all participants regardless of their background." (Fulfilling Lives LSL, Embedding Co-production report)

There has recently been growing interest in co-production amongst service providers and commissioners in the UK. There are opportunities to bring 'experts by experience' together with decision makers to ensure that services and outcome measures reflect the reality of their lives and their recovery journeys.

The lessons from Fulfilling Lives LSL suggest that it is vital to have an established system in place for people with lived experience to share their skills and expertise. This requires organisation, training, mentoring, compassionate leadership, and a culture of learning. Without investment in this, commissioners and service providers facing short-term cycles and demands can find it difficult to properly employ co-production.

Case Study: Opportunity Nottingham's Expert Citizen Group

Opportunity Nottingham is a Fulfilling Lives project funded by the National Lottery Community Fund. Its Expert Citizen Group consists of people accessing services who have made sufficient progress to be able to become involved in informing and supporting the programme's development, ensuring that lived experience is a fundamental component of local system change.

The group is managed by Beneficiary Ambassadors and staff with relevant lived experience. They moderate, manage tensions and advocate alongside Expert Citizens, while ensuring they are supported to avoid burnout, exclusion, or disengagement. At the time of an interim evaluation in 2018, 21 people accessing services had participated in the group, with 'many more' reported to be showing interest.

The Expert Citizen Group contributed to recruitment decisions and processes, commissioning including tender requirements, giving evidence to local and national policy making forums, informing service delivery and system change direction, supporting training and contributing to publicity materials.

For co-production to be effective, it needs to be genuine, meaningful, respectful, and not tokenistic. If you're going to ask people for their input, you must genuinely intend to implement what you learn where possible and to explain why some suggestions might not be possible. People accessing services often feel they have a lot of insights to offer, if only services would listen to them.

"I think you could learn a lot from us and the way that we do things, you know. I think there could be mentors and the peer support have hit on something that the services haven't quite got or have got it and just don't like you and then don't want to have it in their kind of like, you know… Maybe they feel threatened by it in some way, you know, because it's people's jobs at the end of the day as well, so like you know." (Person accessing support)

There is a potential tension where existing practitioners may feel threatened by those with 'lived experience' and may choose not to implement their suggestions. A root cause of this is that the existing practitioner workforce is not representative of people accessing services. Implementing co-production should therefore go alongside supporting people with lived experience to enter and progress in the workforce (see section 7.2 below).

Read more:

- *Re-thinking Outcomes: A practical guide for services designed for people experiencing multiple disadvantage* (December 2021)
- *Re-thinking Outcomes: A guide for commissioners of services designed for people experiencing multiple disadvantage* (December 2021)
- Fulfilling Lives LSL, *Embedding Co-production: Learning and insights* (July 2021)
- Fulfilling Lives LSL, *An Appreciative Model to Co-production* (September 2021)
- Peer research report: Chapters 3 and 4

7

Invest in practitioners

7.1 Core issue: practitioners are not always well equipped to support people accessing support

Service providers and practitioners often have limited resources and face pressure to "do more with less". Supporting high numbers of people can lead practitioners to have little time with each person accessing support, limiting their ability to get a full picture of the person's needs and strengths, which makes it harder to develop tailored support.

> *"People feel very alone with their caseload. People [accessing services] are picked up grudgingly when they have a crisis—they don't feel valued." (Person working in the system)*

These effects are magnified when supporting people experiencing multiple challenges and with experience of trauma.

> *"Every single one has got their difficulties and their struggles and their own traumas and things like that… Sometimes some of the people that we work with would lose a phone or would go off the radar or would become homeless. Or go missing. It's not always straightforward." (Person working in the system)*

Services are not always able to provide adequate training to practitioners, making it challenging for them to respond to the needs of people with experience of trauma or multiple disadvantage. The literature review identified a lack of routine staff training in trauma-informed working in the UK, along with a lack of training about the impact of inequalities. In addition, much of the workforce is not representative of people with experience of multiple disadvantage. This can create distance between practitioners and the people they support.

"And I just, I didn't, I didn't feel like if I wanted to talk about my experience or my past, I didn't really feel that they were the appropriate people because they didn't really have an understanding of the kind of situation and about addiction and stuff like that." (Person accessing support)

Practitioner roles tend to be low-paid, with limited opportunities for training and development. Due to limited resources and a low sector standard for pay, services *"cannot justify"* higher salaries or a bigger training budget. This lack of training, combined with a lack of lived experience of the challenges in people's lives, can hinder the ability for trusting relationships to develop.

Practitioners may have preconceptions about people experiencing multiple disadvantage, particularly if they are not regularly working with this group. People accessing services report they may be forced to present themselves in certain ways so they can be recognised as someone in need.

"I'm now in a place through years of therapy and understanding different hats to wear with different professionals. So, if I'm doing anything about my benefits, I make myself really vulnerable. I make myself dirty, literally, I wear some clothes I've had on the floor that I wore the day before, you know. I don't brush my hair for a benefits interview, you know, that's what they need to see, you know." (Person accessing support)

The combination of supporting high numbers of people, emotionally demanding work, and inadequate training can lead to burnout among practitioners. Practitioners may not be adequately supported in their own wellbeing, again due to limited resources. For example, there may not always be time for adequate debriefs. In some cases, this leads practitioners to be very emotionally invested, which impacts their own wellbeing. In other cases, practitioners may become more emotionally detached to minimise the impact on their wellbeing. This can affect their relationships with people accessing services and make it more challenging for practitioners to be responsive to people's needs.

"[Practitioners] can become hardened to get on with their work and protect themselves." (Person accessing support)

Combined, these factors can lead to conflict between practitioners and the people they support, with people accessing services at times feeling judged or misunderstood. In some instances, services respond with punitive measures such as enforcement or discharge from services. If people have

bad experiences with some professionals, such as the police, this may translate into a lack of trust of other practitioners trying to support them.

> *"I probably can never report anything that could ever happen to me for the rest of my life, because I'm officially labelled a manipulator and a liar. […] not feeling believed and not feeling listened to and not feeling understood, then that's when it builds up a lack of trust of professionals, you know." (Person accessing support)*

Read more:

- Systems map: 'Barriers around engaging with support' and 'Barriers resulting from the way services are set up' sections
- Literature review: Chapters 3 and 4
- Peer research report: Chapters 3 and 4

7.2 How the system can change: invest in practitioners and organisational capacity

Investing in practitioners and organisational capacity has the potential to transform the system for people experiencing multiple disadvantage. We heard time and again in our research that practitioners and services were stretched. High demand and limited resources undermined their capacity to offer longer-term, high-quality, person-led and person-centred services. In the few services where practitioners don't have as many people to support, they are able to help individual people more effectively.

> *"I guess it's small caseloads, you've got the time to work with clients… you can be quite creative and you have time to think… having that time and that flexibility really... is really good." (Person working in the system)*

Training can also make a significant difference to practitioners and those they support. Well-trained and supported staff can feel confident to develop trusting relationships with the people they support, build rapport and manage boundaries in a sensible way. If staff feel more empowered and confident in supporting people facing multiple disadvantage, this can lead to fewer people being turned away from services on grounds of behaviour.

Implementation of trauma-, gender- and culture-informed approaches requires ongoing learning for staff and sustained investment in their organisations. The literature review found a lack of routine staff training in

these approaches in the UK and a need for more money to pay, train, support, and retain staff—especially where care is provided 24 hours a day.

There are some exceptions to this as interest in trauma-informed care and psychologically informed environments begins to grow.[8] For example, St. Mungo's has developed a range of client co-produced training for staff on topics from attachment theory to motivational interviewing; management training to the establishment of reflective practice groups.

Case Study: St Basils' Psychologically Informed Environment

St Basils is a charity providing housing and support to young people in the West Midlands who are homeless or at risk of homelessness. Since 2011, St Basils has developed into a 'Psychologically Informed Environment' (PIE), which uses psychological theories to inform practice, including trauma-informed principles.

PIE provides a flexible but explicit framework that helps staff understand the experiences of homeless young people and gives them psychological 'tools' to work effectively. Working with an in-house Clinical Psychologist, staff receive a programme of on-going training, reflective practice sessions and staff support.

Staff develop reflection skills in order to build collaborative, compassionate relationships, avoid re-traumatisation, and mentor young people to achieve their personal goals. Developing young people's confidence and resilience empowers them to overcome challenges in their lives from previous trauma so they can make a sustained change.

St Basils' evaluation suggests that the quality of relationships between staff and young people impacts outcomes, because overcoming any history of adversity and abandonment requires consistent and stable contact between staff and young people. A trusting relationship like this must be nurtured with time and attention, which has practical implications for both staff workload and the length of time young people stay at St Basils.

For practitioners to work in a trauma-informed way, they need to know how to maintain their personal and professional boundaries so they can protect their own wellbeing and be consistent in their approach towards people they support. Alongside training, the literature recommends prioritising peer-led supervision and earmarked funds that go directly to supporting staff mental health and wellbeing.

"Of course, boundaries are important but boundaries should be shaped in a way where you're not felt that you are… in the boundary, you know what I mean, like, and you don't want to actually talk to the person because you feel that

[8] Psychologically Informed Environments (PIEs) are services where the day-to-day running has been designed to take the psychological and emotional needs of people with these experiences into account.

they are kind of mistrusting you, you know?"
(Person accessing support)

Case Study: Tomorrow's Women Glasgow

Tomorrow's Women Glasgow is a one-stop shop to meet the complex needs of high-risk female offenders. Tomorrow's Women Glasgow prioritises supervision for staff, provided four weekly by the team lead. In addition, they have established weekly complex case discussions and regular training sessions so that staff, even if they are not directly 'treating' symptoms of Complex PTSD, develop a trauma-informed understanding of the women's presenting problems.

Read the full case study in the literature review, page 33.

Involving people with lived experience when training practitioners can improve services as well as break down power dynamics in the system. As well as benefiting practitioners, it can also have therapeutic value for the people with lived experience who are able to share their insights.

"And to see them at the end of the training where their opinions have actually genuinely changed was so rewarding, to get that feedback. Was quite... it really, really, helps me. I saw it as part of my therapy. I saw it as an extension of the therapy I was receiving at the time." (Person accessing support, talking about their experience of training professionals within the system)

One of the issues uncovered in our system map was that the practitioner workforce is not representative of the people they support. Training is one way to overcome the lack of expertise from lived experience, but to fundamentally change this dynamic we need to support people with lived experience to enter and progress through the workforce. For example, service providers could develop employment pathways and progression for people with lived experience—these should move beyond practitioner roles and include roles in all departments and at all levels of a service. This would improve the relationship between services and the people they support. Our peer research found that people feel more comfortable talking to someone who understands them.

"That's what's important to the people that come to see peer supporters. It's, it's about being able to have a chat and a cup of tea and a cup of coffee or whatever, and you know, with somebody that really understands where they're coming from." (Person accessing support)

All of this requires changing culture and attitudes, as well as investing in people and organisations, which means improving how funding flows through the system (see section 8.2 below).

Read more:

- Systems map: 'Barriers around engaging with support' section
- Literature review: Chapter 4
- Peer research report: Chapter 4

8

Improve funding and policy

8.1 Core issue: short-term funding flows and siloed policy decisions can lead to ineffective services

Many of the issues above—from limited resources to not joining the dots between people's connected issues—have their roots in the funding and policy environment. Our system mapping workshops identified a range of issues with how funding flows through the system and how policy decisions are made, which ultimately affect people's experience of services.

A focus on short-term funding means that service providers can find it difficult to access multi-year sources of income. This creates instability for many service providers, who are often not able to offer staff longer-term contracts or offer people accessing services a guarantee that the service will still be there in the future. This can contribute to high staff turnover and a lack of trust between practitioners and people accessing services. Services also find themselves spending a lot of time and resources applying for funding or contracts instead of delivering services.

> *"Services feel like 'Oliver Twist' – constantly asking commissioners 'can we have some more [money]?'" (Person working in the system)*

Whilst there are lots of commissioners working hard to offer opportunities to smaller organisations or groups of organisations, the way that commissioning systems are set up can work against this. Commissioners are often incentivised to give contracts to larger organisations that can achieve economies of scale, take on greater financial risks, demonstrate 'value for money', use 'tested' approaches, and have the systems required to ensure quality and monitor outcomes. Smaller organisations may lose out during competitive commissioning processes. Without access to sustainable sources of income, these organisations can end up in a precarious position, with limited visibility of their future income.

Specialist organisations who target specific groups, delivering tailored services such as culturally-informed or gender-informed support, tend to be

smaller. As a result, competitive funding processes, which incentivise a 'one size fits all' approach, can put further pressure on organisations supporting these groups and can contribute to people's needs not being met.

"Charities are pitted against each other" (Person working in the system)

The emphasis on established models and 'tested' ways of working also discourages innovation. There is little incentive to trial new approaches, which can lead to a culture in which learning and adapting is not valued. Though there may be some small adaptations along the way, these are unlikely to be enough to lead to significant change.

This risk-averse approach can solidify the system into continuing to do things in broadly the same way, while expecting different results. Moreover, the outcomes targets set by commissioners may not be able to capture the nuance of how much an individual values a service and the difference it makes to their lives. Commissioners often require a higher level of 'hard' outcomes targets delivered for the same money. Relational or 'soft' outcomes are trickier to measure, so it is harder to convince funders that they are important.

"Measures are based on what you can see – you don't measure softer things." (Person working in the system)

Funding flows tend to not only be short-term but also siloed by need. Commissioners focus on particular areas within their remit such as homelessness, domestic violence, or substance use. This means that people accessing multiple services may receive inconsistent and unconnected support across them. Service providers and practitioners must also navigate a fragmented and complex network of provision if they want to make onward referrals. This complexity is driven by the existence of multiple funding sources, from local authorities, health commissioners, national funding streams, and voluntary sector grants.

"There isn't a map of services – 'this is who you talk to for each of the issues'." (Person working in the system)

Commissioners can feel constrained by the rigid structures around them and the conditions attached to the funding that they receive. They often operate within hierarchical management structures and commission services based on policy priorities that are passed down to them.

"As a commissioner, I'm not on top in my organisation. There are processes and pressures above me." (Person working in the system)

Commissioners are often driven to focus on short-term funding cycles. Funding from central government can be contingent on local authorities spending funds within an allocated time, meaning they have little flexibility. This can further encourage commissioning to focus on crisis response rather than preventative interventions.

At the systemic level, these dynamics are partly driven by short-term electoral cycles at the national and local level. Historic and ongoing cuts to local authority service budgets have also shrunk the available resources for services supporting people experiencing multiple disadvantage. As budgets get smaller or fail to rise with increasing demands, it can be difficult for commissioners to maintain services, and even harder to take risks with new approaches.

All this stifles innovation and limits change within the system. Commissioners may struggle to test new approaches, work across different focus areas or learn from people who access services. They may focus exclusively on the area they work in, with little time or opportunity to collaborate with colleagues focused on other areas.

"Nobody is looking at how all the different areas of need or services fit together. Services are commissioned separately." (Person working in the system)

Commissioning decisions are often rooted in policy decisions made by people who must work within their own constraints. Policymakers must account for numerous, often competing, priorities when making policy decisions. These decisions are often made amidst a context of limited time, resources, and room for manoeuvre. This can restrict policymakers' ability to effectively consider the realities of people experiencing multiple disadvantage. In particular, policy decisions can:

- **Be siloed by the different needs of an individual:** Policymakers often have to make decisions focussed on solving a specific problem such as homelessness. They may not always be able to develop policy collaboratively with policymakers working on other connected issues. Silos at the national policy level trickle down through the system, influencing funding streams and ultimately resulting in services that do not adequately meet the needs of people experiencing multiple disadvantage.
- **Be risk-averse:** Policymakers tend to focus on 'tried and tested' approaches. Limited time and resources means limited capacity to adapt to new ways of ways of working. As the government is accountable to the public, policymakers are responsible for ensuring public money is

not wasted. This means they may be cautious to try new or unproven approaches. In addition there may also be a culture of fear or blame if the results deviate from expectations. This culture can act as a barrier to change, even when across the system there may be a desire to drive systems change.

- **Not prioritise prevention:** Politicians often seek to focus on 'wins' achievable during their political terms, with these priorities potentially changing regularly. As a result, some needs may be prioritised over others, with a particular focus on issues that are *"cheap, easy, visible, and achievable in [short political terms]"*, as one person working in the system described it. This way of working can make it more challenging to address the underlying causes driving visible need. For example, although domestic abuse is one of the leading causes of both homelessness among women and their presence in the criminal justice system, policy may focus on tackling more visible issues such as street homelessness, rather than supporting preventative initiatives.
- **Be gender-neutral:** The literature review found that policy making for people experiencing multiple disadvantage has tended to focus on a set of common issues: homelessness, offending and substance use. This has led to a predominant focus on men—even when services are intended to be gender-neutral—because men present as having higher rates of these three issues. More recently, there have been calls for women's specific needs (such as their experiences of gender-based violence) to be better considered by policy, strategy and services.
- **Struggle to implement learnings from research:** Much policy does draw on areas of effective practice, but it can be challenging for policymakers to account for numerous priorities in their decision making. Because of this, it is not always possible to implement recommendations from research or use evidence about models used elsewhere to inform decision making.

Read more:

- Systems map: 'Barriers resulting from Government and policy priorities', 'Barriers resulting from commissioning priorities' and 'Barriers resulting from the way services are set up' sections
- Literature review: Chapters 2-4

8.2 How the system can change: take a longer-term view with funding and policy

Funding flows and policy frameworks are some of the hardest things in the system to shift. The issues identified above are deeply embedded and held in place by established structures, cultures, behaviours, power dynamics, attitudes, and beliefs. Nonetheless there are innovative examples that show how the system can change. These include the National Lottery Community Fund's Fulfilling Lives programme and the Changing Futures programme funded from the government's Shared Outcomes Fund with aligned funding

from the National Lottery Community Fund. Both these funding programmes test new ways of bringing together public and community sector partners so that people receive joined-up and person-led and person-centred services which work for them. Crucially, both programmes invest in long-term change: Fulfilling Lives is an investment over eight years whilst Changing Futures is a three-year programme.

At a local level, many funders and commissioners are testing structures that support a more joined-up approach. For example, joint commissioning models and alliance contracts can reduce competition for funding and create a structure for organisations to collaborate over the long term.

Case Study: Plymouth Alliance for Complex Needs

The Plymouth Alliance was established as a means to work across organisational silos to achieve the city's vision of improving population-based wellbeing and reducing inequalities in health. It integrates commissioning, health and social care and a system of health and wellbeing. Plymouth City Council has legally pooled all of its monies with the Western Locality of Devon Clinical Commissioning Group (CCG) and created a single budget of over £600 million (gross) and an integrated, co-located commissioning team of CCG and council staff.

This integration laid the foundation for deeper collaboration, which began in 2012 when a group of commissioners and leaders of provider organisations in Plymouth began to work together. In 2019, an Alliance Contract was awarded to seven provider organisations who support adults with complex needs so that their lives are improved. Along with three commissioners, the CEOs form an Alliance Leadership Team of ten members, operating on a principle of one person one vote and unanimous decision making.

The contract is for up to 10 years (5+2+2+1) and all of the annual spend (£7.7 million) is devolved into the Alliance which has autonomy to spend it as it chooses. In addition, the Alliance has a subcontracting relationship with other providers to deliver approximately 20 additional services. Alliance partners provide housing advice and support, access to temporary and settled accommodation, treatment and support regarding substance use, including prescribing. The Alliance aims to coordinate a complex needs system which will enable people to be supported flexibly, receiving the right help, at the right time, in the right place.

Creating spaces for conversations between policymakers and people with lived experience is another way for policy decisions to better meet people's needs. In our systems mapping workshops, we heard how policymakers do not typically engage directly with people experiencing multiple disadvantage. This was due to a lack of opportunities and societal stigma around the challenges experienced by those accessing services. This stigma can give rise to fear and a lack of trust between policymakers and people accessing services. Yet, without engaging with people experiencing multiple disadvantage, policymakers will struggle to understand the realities of their lives. Initiatives such as the Fulfilling Lives National Expert Citizens Group

help to create opportunities for dialogue between policymakers and people with lived experience.

Case Study: National Expert Citizens Group

The National Expert Citizens Group (NECG) is the lived experience representative group for people using services in the National Lottery Community Fund's Fulfilling Lives programme. It aims to ensure lived experience shapes system change and creates future services that are co-produced, accessible and designed for people who have experienced multiple disadvantage.

In 2020, the NECG explored several questions to inform Dame Carol Black's independent review of drug use prevention, treatment and recovery.

1. How could we make it easier for people to access drug treatment and recovery services, and stay in contact with those services?

2. How can we ensure the mental health needs of people in treatment are met?

3. What is the best way to meet the employment and housing needs of those in treatment and recovery?

4. What else stops people recovering and why might they relapse?

NECG members discussed these questions with other people with lived experience in their local Fulfilling Lives area. They compiled over 20 reports to feedback at regional meetings, and the consistent themes were summarised into a single report for Dame Carol.

NECG members also had the opportunity to present the findings to Dame Carol directly. This allowed her to ask questions of the members, and ensured the voice of those with lived experience of drug use, drug treatment and recovery was reflected in her final report.

Dame Carol commented: "The expert reference group kept my feet firmly to the fire and on the ground. The voices of those with lived experience of drugs have been urging us forward throughout, I hope not in vain, and I thank them for their invaluable testimony."

Read more:

- Systems map: 'Barriers resulting from Government and policy priorities', 'Barriers resulting from commissioning priorities' and 'Barriers around shaping and designing support' sections
- Literature review: Chapter 4
- Peer research report: Chapter 4

9

Final thoughts

The five core issues summarised in this paper contribute to a system which does not effectively support people experiencing multiple disadvantage. These systemic issues are deeply embedded, but our research shows how change is possible.

A concerted effort by policymakers, commissioners and service providers to improve access and transitions, meet people's specific needs, deliver person-led services, invest in practitioners, and improve funding and policy decisions has the potential to shift the way the system works. These changes will enable people experiencing multiple disadvantage to receive effective support and reach their full potential.

Our research shows the value of listening to people to understand how the system works and how it can change for the better. People are at the heart of the system, understand it, and can make a difference to how it works. Two quotes from a researcher and a person accessing support highlight this:

"As I interviewed people it came up time and time again in many forms and guises, that, regardless of how we choose to dress it up, when you strip everything away it all adds up to the same thing – humanity – and being listened to, heard and valued. This seemed to be the difference needed to help or challenge previous beliefs and perspectives and the catalyst to whether they were more likely to experience success or not in their journey." (Groundswell researcher)

"the system itself, the building, is just the building, you know what people walk through. And the service, like you said, it's just the service, it's just like, you know, it doesn't actually care about you, as such, that's not the way it works, is it? It's the individuals within the service who actually care about you." (Person accessing support)

We hope that our research will inspire action across the system, as well as showing what we can learn from listening to people with lived experience.

10

Further resources

Research partnership publications

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- NPC (2021) *Systems mapping multiple disadvantage*, https://fulfillingliveslsl.london/systems-barriers-and-challenges-at-play-for-people-experiencing-multiple-disadvantages/
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- NPC, CRESR and Groundswell (2021) *Re-thinking Outcomes: A practical guide for services designed for people experiencing multiple disadvantage*, https://fulfillingliveslsl.london/re-thinking-outcomes-guide-for-services/
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Fulfilling Lives LSL publications

- Fulfilling Lives LSL (2021) *Local Evidence Submission: Professor Dame Carol Black's: Prevention, treatment & recovery independent review of drugs,* https://fulfillingliveslsl.london/local-evidence-submission-professor-dame-carol-blacks-prevention-treatment-recovery-independent-review-of-drugs/
- Fulfilling Lives LSL (2021) *Dual Diagnosis and access to support*, https://fulfillingliveslsl.london/dual-diagnosis-and-access-to-support/
- Fulfilling Lives LSL (2021) *Embedding Co-production: Learning and insights*, https://fulfillingliveslsl.london/embedding-co-production-learning-and-insights-from-fulfilling-lives-lambeth-southwark-lewisham-part-1/
- Fulfilling Lives LSL (2021) *An Appreciative Model to Co-production*, https://fulfillingliveslsl.london/co-production-whats-working/
- Fulfilling Lives LSL (2021) *Barriers to Moving into and Remaining in Settled Accommodation,* https://fulfillingliveslsl.london/breaking-the-cycle-of-homelessness/
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- Fulfilling Lives LSL (2022) *Annual Learning Review 2021*, https://fulfillingliveslsl.london/annual-review-2021/
- Fulfilling Lives LSL (2021) *Power of Language tool*, https://fulfillingliveslsl.london/power-of-language-tool/
- Fulfilling Lives LSL (2021) *In Opposition of The Nordic Model: Evidence against the Sexual Exploitation Bill 2019-21*, https://fulfillingliveslsl.london/our-response-to-the-sexual-exploitation-bill/
- Fulfilling Lives LSL (2020) *Submission to the Women & Equalities Committee 2019*, https://fulfillingliveslsl.london/submission-to-the-women-equalities-committee-inquiry/
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- Fulfilling Lives LSL (2021) *Women's Health Strategy*, *https://fulfillingliveslsl.london/womens-health-strategy/*

Research partnership podcasts

- Groundswell and experts by experience (2021) *The Missing Piece*, https://www.mixcloud.com/Groundswell1/the-missing-piece/

- Groundswell and experts by experience (2021) *Listen to me!*, https://www.mixcloud.com/Groundswell1/listen-to-me/

Research partnership event recordings

- Fulfilling Lives LSL, NPC, CRESR, Groundswell and experts by experience (2020) *Trauma, gender and culture-informed care: How to embed it in your services*, https://www.youtube.com/watch?v=0YdUAcquxJI
- Fulfilling Lives LSL, Groundwell and experts by experience (2021) *Multiple disadvantage and access to services: peer research findings*, https://www.youtube.com/watch?v=XjAC8i381Sw

Other resources referenced in this report

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Reports from the National Fulfilling Lives evaluation

- CFE Research (2020) *The role of lived experience in creating systems change*, https://www.fulfillinglivesevaluation.org/wp-admin/admin-ajax.php?juwpfisadmin=false&action=wpfd&task=file.download&wpfd_category_id=324&wpfd_file_id=6821&token=77727eb59929ca7b42d7b1079a4f4b30&preview=1
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