People's experiences of multiple disadvantage in Lambeth, Southwark and Lewisham: A peer research project

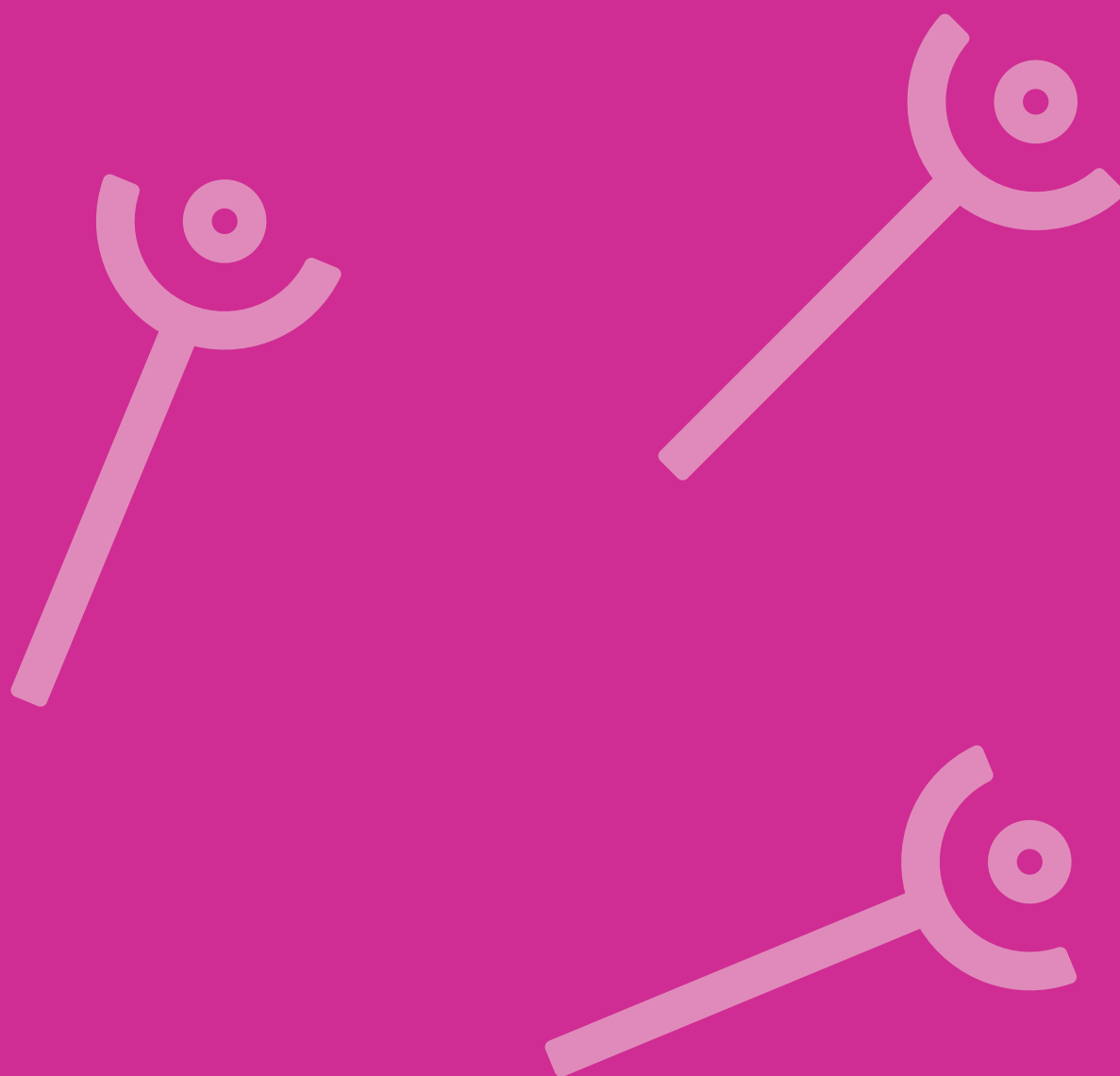Martin Burrows, Sarah Hough, Stephan Morrison, Dr. Suzy Solley and Experts by Experience

July 2021

FULFILLING LIVES
LAMBETH SOUTHWARK LEWISHAM

COMMUNITY FUND

NPC

Groundswell Out of homelessness

Sheffield Hallam University | Centre for Regional Economic and Social Research

Acknowledgements

We would like to say thank you to the services in Lambeth, Southwark and Lewisham who supported us with this research. A massive round of applause to the five experts by experience[1] and two community partners from [Fulfilling Lives Lambeth, Southwark & Lewisham](#) (FLLSL) for your enthusiasm, passion and commitment. We have thoroughly enjoyed working with you and you have cheered up lockdown immensely. Lastly, we thank the people who took time to participate; thank you for sharing your stories with us, in what was for many of you a difficult time. We hope that this research will be a step towards ensuring people experiencing multiple disadvantage are able to access the support they need. This research project is funded by The National Lottery Community Fund.

About Fulfilling Lives Lambeth Southwark and Lewisham

The FLLSL programme is funded by The National Lottery Community Fund and is part of the [National Fulfilling Lives Programme](#).[2] Certitude is the lead agency of the Fulfilling Lives programme in Lambeth, Southwark and Lewisham, delivering the programme in partnership with Thames Reach, South London and Maudsley NHS Trust and other strategic partners. The FLLSL programme has the following approaches to working:

- **Co-production:** giving equal value to the voices of both the decision-makers and the people we support, so that all opinions are heard and respected equally
- **Service delivery**: working alongside people and services, learning and testing different interventions to change the lives of people experiencing multiple disadvantages for the better – now and in the future
- **System change:** making an impact on the way people are supported by influencing policy and practice, locally and nationally

Systems change activities at FLLSL focus on key priority areas, derived from the learning and experience of practitioners and the people directly supported over the first four years of the programme. The system change priorities focus on access, transitions and relationships, and system behaviour. The work of FLLSL is underpinned by the principles of trauma, gender and cultural awareness and co-production. To find out more visit https://fulfillingliveslsl.london/.

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[1] 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'.
[2] For the FLLSL website and annual review see [here](#).

About Groundswell

Groundswell works with people with experience of homelessness, offering opportunities to contribute to society and create solutions to homelessness. Participation is at our core because the experience of homelessness is crucial in making decisions that affect lives and ultimately help people to move out of homelessness.

About the partnership and this report

To pursue the goal of systems change, FLLSL entered a new research and learning partnership with New Philanthropy Capital (NPC), Groundswell and the Centre for Regional Economic and Social Research (CRESR) in 2020. The research and learning partnership combines expertise in systems change, influencing policy-makers, peer research, and trauma-, gender- and culturally-informed approaches. Previous outputs include a systems map, a literature review and an action guide on trauma-informed approaches for services and for people experiencing multiple disadvantage.
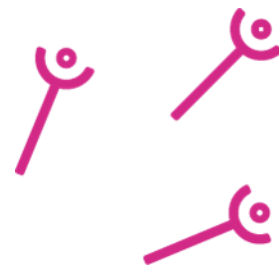
This report complements the wider programme of work. The activities of the research and learning partnership focus on the key systems change priorities identified by the FLLSL programme.[3] Using a peer research methodology, we focus on understanding people's experiences of accessing services and support, the transitions they make, and how the broad system of support operates for people experiencing multiple disadvantage. The research was guided by the following research aim:

> "To better understand the complex 'system' that people experiencing 'multiple disadvantage' have to go through and strengthen the case for 'systems change'".

In addition to this aim, we have followed the FLLSL philosophy that "it is not the person that is hard to reach rather it is the system that is hard to access and needs to change".
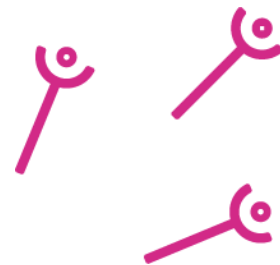
Experts by experience and team members at FLLSL with experience of multiple disadvantage have guided this research. The following report structure is based on categories identified by the experts by experience, and the themes of access, transitions and system behaviour feature throughout. Many of the sections overlap reflecting the interconnectivity of the issues.

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[3] For more information on all phases of the project, please go to: http://groundswell.org.uk/fulfilling-lives-lambeth-southwark-and-lewisham/

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Introduction

1.1 A note on the 'system'

It is important to take a moment to describe what we mean by the 'system' because this understanding has guided this research and the FLLSL programme more broadly.

> "A system is a configuration of interaction, interdependent parts that are connected through a web of relationships, forming a whole that is greater than the sum of its parts." (J. Holland)

As detailed in the [systems map](#) for this research, a systems thinking approach "encourages us to understand the complexity of systems, and to move away from looking at individual events or interventions towards understanding how interconnected causes and systemic structures create these one-off events. 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."

With this approach to systems thinking we look beyond the issues that an individual is facing to how these issues are experienced in the context of the wider system.

1.2 Defining multiple disadvantage

The Fulfilling Lives programme considers people to have experienced multiple disadvantage if they have two or more interconnecting experiences of homelessness/insecure housing, mental ill health, substance use or contact with the criminal justice system. The term 'multiple disadvantage' recognises the significant overlap between groups affected by multiple and extreme forms of disadvantage. As highlighted by Woodall et al (2018)[i], "a plethora of terms have been used to describe these groups" including "'severe and multiple disadvantage', 'multiple disadvantage', 'multiple disabilities',

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'multiple impairment', 'dual diagnosis'[4], 'high support needs', 'complex health needs' and 'multiple and complex needs'".

Terminology and labels are, of course, useful in helping to address and highlight issues people face, but, as we argue in this research, 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. What is deemed appropriate language is subjective and continually evolving. In this report we have tried to pay particular attention to the language used with the realisation that this is an ongoing process.

In recent years, there has been a growing interest in the connection between the issues of homelessness, substance use, mental ill health, contact with the criminal justice system, experience of violence, childhood trauma and poverty (Fitzpatrick, Johnsen, & White, 2011[ii]; Revolving Doors Agency, 2011[iii])([iv]). The FLLSL programme is borne out of a recognition of these overlapping connections and presents further evidence and learning around people's experiences of multiple disadvantage, as well as systems behaviour. The literature review[5] for this research and learning project brought together broad, multidisciplinary evidence about access to services, transitions within services, and how the system behaves for people facing multiple disadvantage.[v]

> *"We still categorise people in separate boxes defined by single issues. So, a person who takes drugs to deal with childhood trauma, who falls into offending as a consequence, and loses their home when entering prison acquires three quite distinct labels. Each of these labels triggers a different response from statutory and voluntary systems, different attitudes from the public and media, different theoretical approaches from universities, different prescriptions from policy makers."* (Bramley and Fitzpatrick, 2015: 4)

Over five years on from Bramley and Fitzpatrick's research, and despite knowing what the issues are, and the ways in which the system fails people, these issues continue to perpetuate. This research adds to the important body of evidence on multiple disadvantage. Important studies from Woodall et al (2018), Ava (2018)[vi], Revolving Doors Agency (2011) and also the national Fulfilling Lives evaluation[vii] and the FLLSL programme[viii] have used peer methodologies to explore multiple disadvantage. Like these studies, the voices and experience of people with lived experience are at the centre of this report; in addition, from the insights shared by participants you will find pieces of writing and poems from experts by experience involved in the research process.

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[4] Dual diagnosis is a term used to describe co-existing mental ill health and substance use.
[5] Find the literature review here: https://www.thinknpc.org/wp-content/uploads/2020/09/FLLSL-Lit-Review_FINAL-September-2020-1.pdf

1.3 Peer research methodology

The research project employed a peer research methodology with input from researchers with experience of multiple disadvantage (both the experts by experience and team members) throughout the co-design and delivery of this project. The peer research approach is in line with FLLSL's core focus on co-production.

Peer research is commonly understood as a type of participatory research. Definitions of peer research vary, but it is generally agreed that peer research *"recognises that individuals within any community being researched are themselves competent agents, capable of participating in research on a variety of levels, including as researchers"* (Higgins et al, 2007: 105).[ix] This means that rather than simply being passive research subjects, peer researchers are actively engaged in the research (O'Reilly-de Brún et al, 2016). The aim of peer research is to make positive change in the 'communities' of research (Wadsworth, 1998)[x] and in this case for people with experience of multiple disadvantage. The degree to which peer researchers can be involved in the process varies; this can be thought of as a continuum. Peer researchers can be involved in a lighter way, for example participating in an advisory panel directing the research. Alternatively, peer researchers can be more immersed and involved in the entirety of the research process, including research design, data collection, data analysis, and write up (Lushy, 2017). This type of peer research, where researchers are involved in the entirely of the process, is often described as the 'partner model' (Roche, Guta and Flicker, 2010: 3)[xi]. As experts by experience volunteers were involved in all stages apart from data collection and Groundswell team members were involved in the entirely of the process, therefore we would describe this research as the 'partner model'.

Five experts by experience were recruited to participate in the entirety of the process. Experts by experience took part in various online training sessions (see Appendix 1) to prepare them for conducting telephone interviews; however, because of the rising number of COVID-19 cases in late December 2020 and early 2021, it was not possible to bring everyone together in person to conduct telephone interviews. Despite this, experts by experience were involved in a range of core research activities including designing the research questions; helping to recruit participants; designing the consent forms and information sheets; feeding back on case studies; reflective writing and drawing; and developing a podcast (see Appendix 1). We hope that as the COVID-19 situation improves the experts by experience will be able to support data collection in the subsequent phases of this research and learning partnership project. On the next page they share their experiences of being involved in the project; we also turned some of these into haikus (short poems) during a reflective and creative writing session. Working together as a group was enjoyable and beneficial to our wellbeing, especially having the opportunity to share our experiences during lockdown.

Reflective Writing
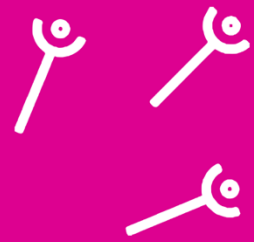
Tuesday Jam Sessions

Little did we know

like seeds we could die

in soil of selflessness.

Fertilised with curiosity

showered with words

of hope.

We emerged from darkness

radiant in colour

scented in passion

and pioneer.

Each testing, proving

how far we go

with character

together

in weakness and strength.

Fading formality

removing our layers

with each truth we speak.

We trespass into friendship

kindness and authenticity

unawares.

This is the happening

in spaces

we dared to be free.

"

"The things I've enjoyed most about the group is the comradery and the really good company. The things I've found hard is when we do big groups and I don't know hardly anyone. It's not a bad thing. Just different to what I'm used to. (Ethan, 2021)

"

A sense of kindness

Accommodating our needs

Giving back somehow.

(Christina, 2021)

"

Being together

Making change. Past and present

I'm feeling your growth

(S ,2021)

Research methods

This peer research employs a qualitative approach, using in-depth, semi-structured interviews. It was deemed that in-depth interviews would be more appropriate than quantitative measures for capturing the nuances and complexity of the issues faced by people when they experience multiple disadvantage. We captured demographic information through a series of closed questions at the end of the interview and this data will be presented later in this chapter.

A total of 41 interviews were completed in late December 2020 and early 2021 with people either living in or receiving support from services in the London Boroughs of Lambeth, Southwark, and Lewisham. Interviews were conducted with Groundswell staff peer researchers over the telephone due to COVID-19 restrictions. To be eligible for the study, participants had to have experienced two or more of the following issues: mental ill health, homelessness, substance use and/or contact with the criminal justice system. Participants were recruited through several different services in the three boroughs including mental health services, probation, drug and alcohol services, homelessness services, hostels, foodbanks and other voluntary organisations. Some of these services involved in supporting the research were already known to the partnership and others were new to the partnership. Given the challenges of recruiting people during the pandemic the support of these services was integral in recruiting participants. In addition to telephone interviews, an online survey was designed for participants to fill in independently.

Analysis and writing

Interviews were analysed using thematic analysis. Experts by experience were integral in thematic analysis and participated in a series of workshops to support the analysis process. Experts by experience were also involved in the writing of the report and gave feedback on the report. You will see excerpts of their writing throughout the report.

Limitations

The main limitations of the research were with the constraints of the COVID-19 lockdown and how it affected the sample and the methodology. This research was initially intended to engage up to 200 people through face-to-face surveys with volunteer experts by experience; however, with the constraints of lockdown we had to conduct the research by telephone. We were aware from other studies that we have conducted during the pandemic that the number of participants we would be able to access would be limited. We changed the methodology to do in-depth qualitative interviews. Given the complex nature of multiple disadvantage this change in methodology
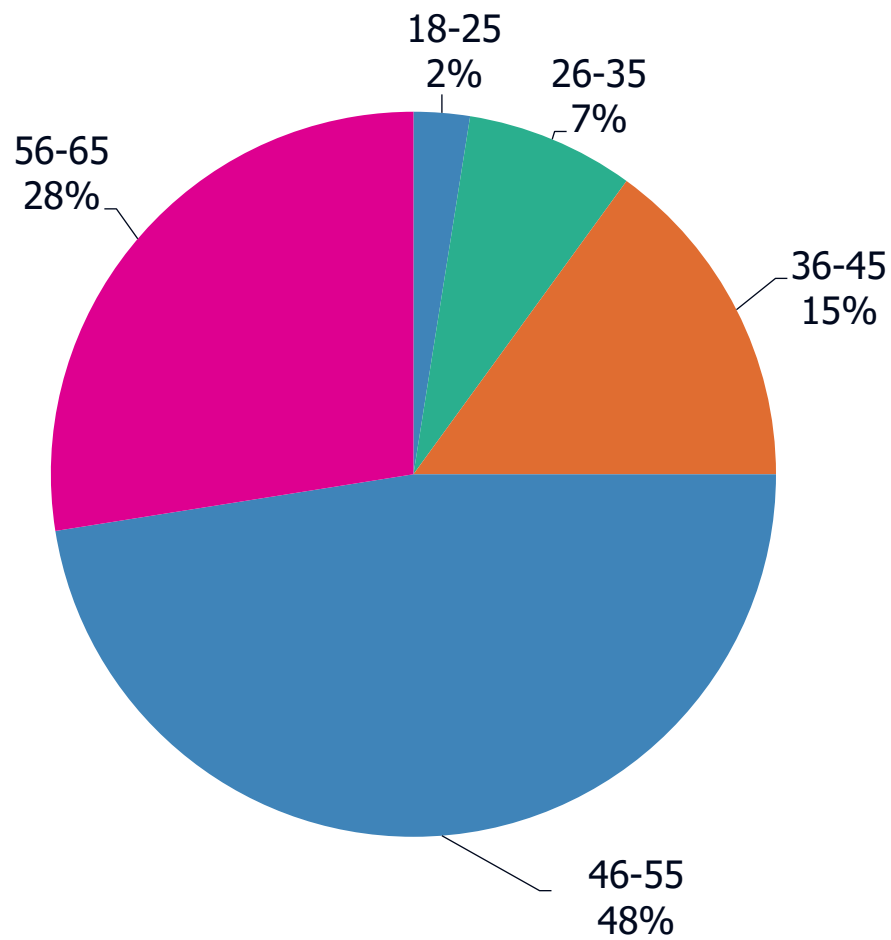
worked well, but it did mean that as we were conducting telephone interviews it was not appropriate for this research to be conducted by volunteers in their accommodation. Shifting to telephone interviews also had an implication on the type of people we spoke to. Face-to-face research is particularly important for being able to capture the experiences of people who find it difficult to talk on the phone and/or who have challenges accessing technology, so it is likely that this study omits this group of people. Moving into the next phase of this research, and as the lockdown lifts, we hope to conduct face-to-face research.

We recruited more research participants in Lambeth than in Lewisham and Southwark (see demographics below). As a result, the data collected is skewed towards the experiences of those living or seeking support in Lambeth. We also struggled to recruit younger participants; this may be because participants were recruited through organisations which tend to work with people who are older. In the next phase of the research, we hope to redress these imbalances by recruiting more people from Lewisham and Southwark, and more younger people.

Demographics

To give some context to the findings, this section explores the demographic profile of the research participants. As we know from previous evidence, age, gender and sexual identity can affect the way people access and engage with support services. In terms of gender, 40% described themselves as women, 57% as men and 3% as gender fluid. Most participants (76%) were 46 years or older; only 9% were 35 years old or younger.

Figure 1: Age of participants (years)

- 18-25: 2%
- 26-35: 7%
- 36-45: 15%
- 46-55: 48%
- 56-65: 28%

Figure 2: Sexuality of participants

- Prefer not to say: 5%
- Other: 3%
- Bisexual: 8%
- Gay: 12%
- Heterosexual: 72%
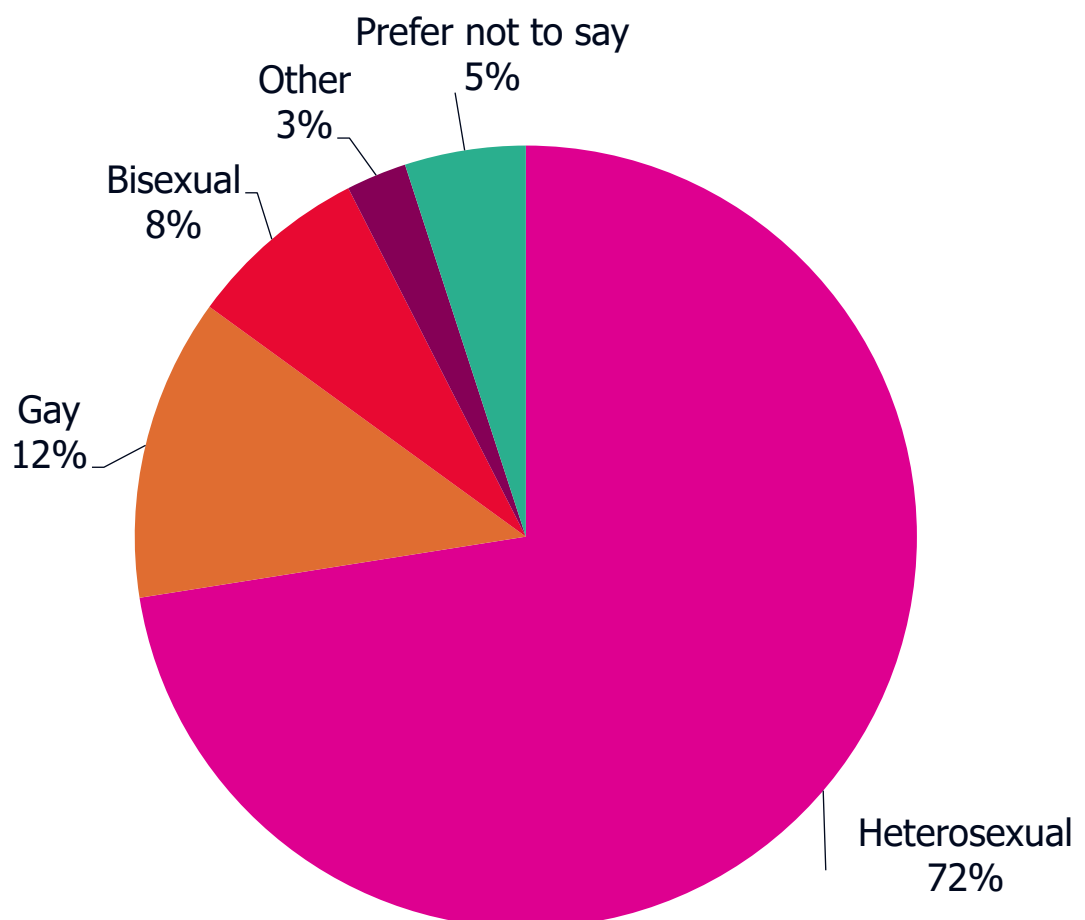
Figure 3: Ethnicity of participants

- Prefer not to say 3%
- Other 18%
- Dual ethnicity 7%
- White Irish 10%
- Black African 5%
- White European 5%
- Black British 10%
- White British 42%
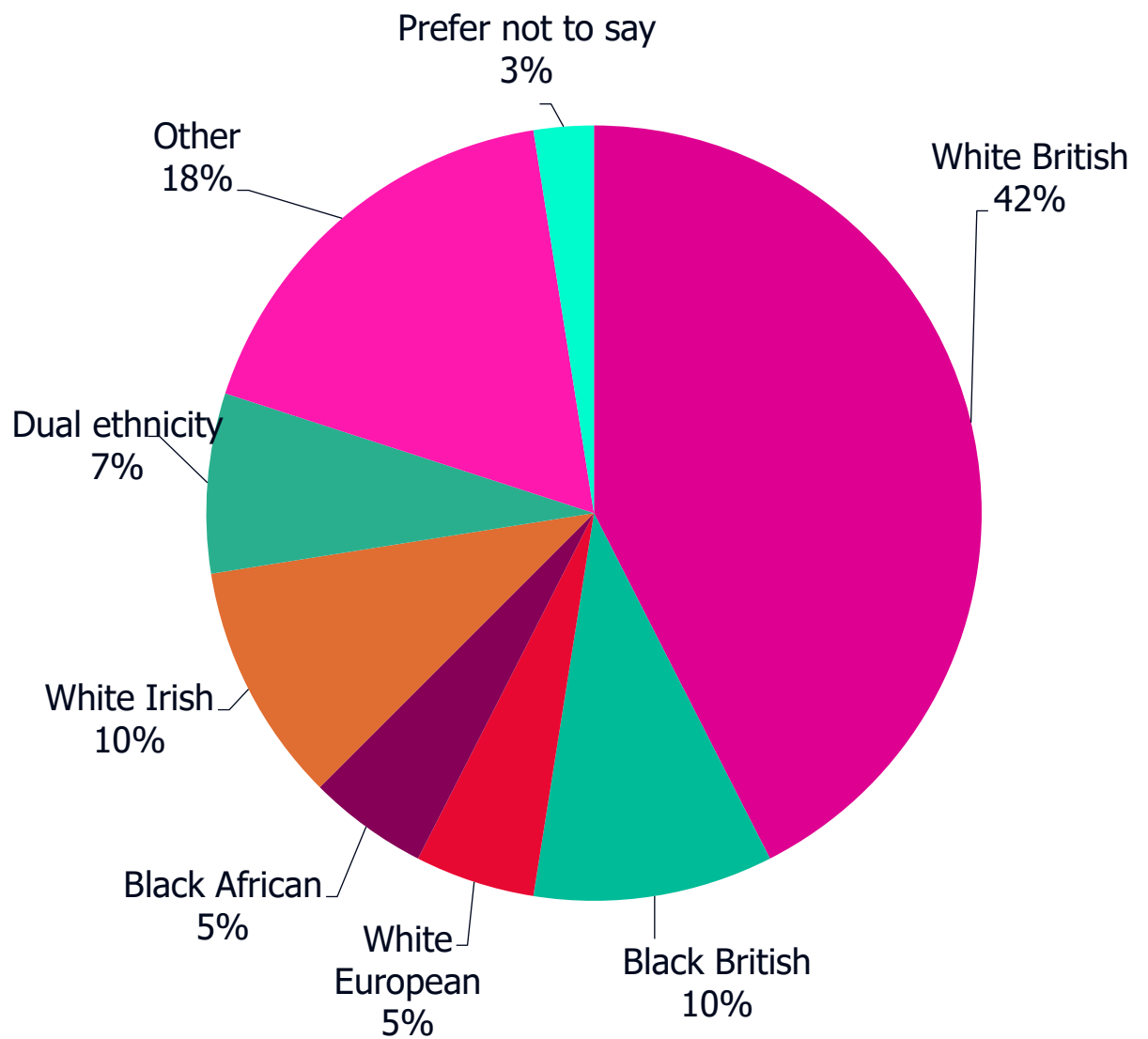
Figure 4: Boroughs in which participants were living and accessing support

The graph above shows that most participants were either living or accessing support in Lambeth. Although the sample does not claim to be fully representative of the target population across the three boroughs, the demographic profile does indicate that a certain diversity has been captured with the exception of younger participants.
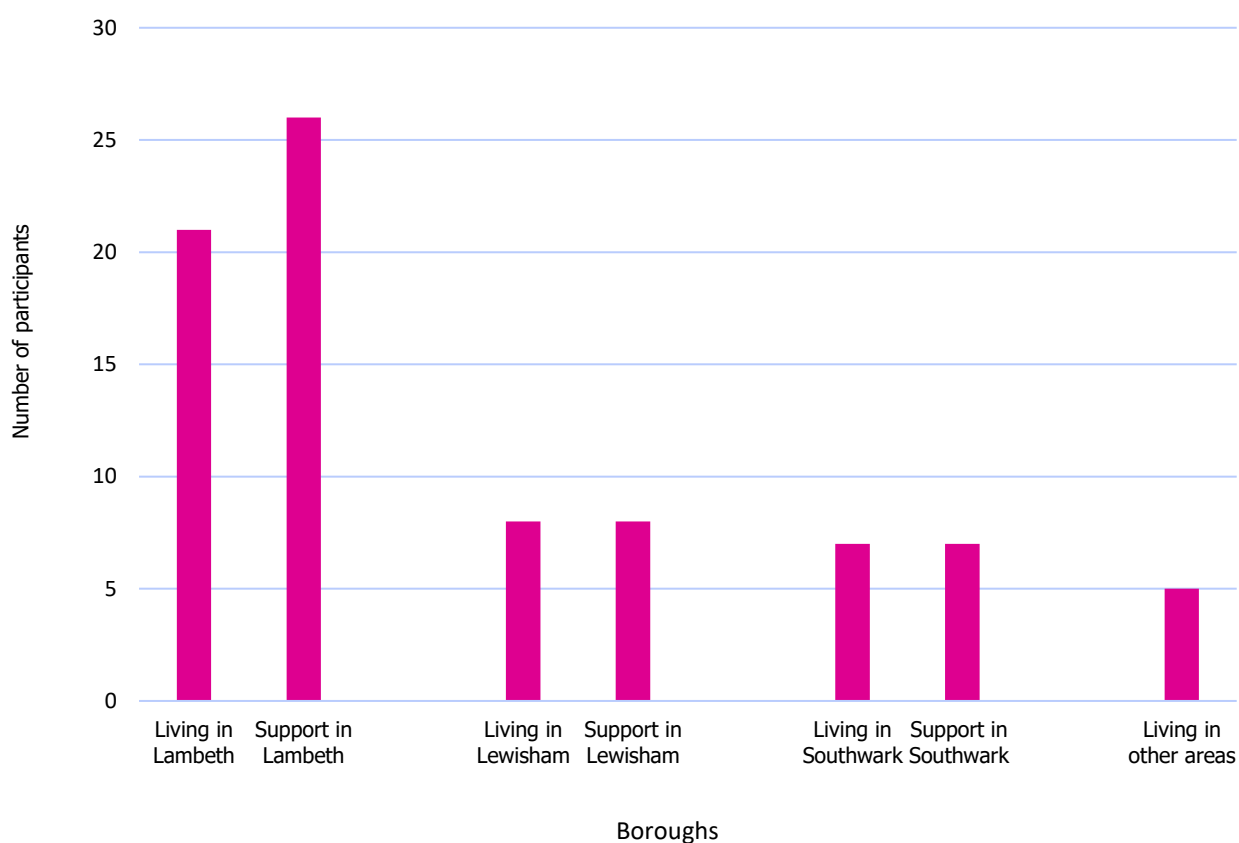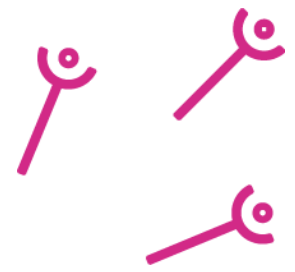
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Where are you in your journey?

Key Messages

- **Participants were experiencing a combination of challenges. Nearly all (90%) were either experiencing or had experienced mental ill health, homelessness (85%), substance use (73%) and/or contact with the criminal justice system (48%)**

- **Participants were at different points in their journeys.[6] Some felt they were "on the way up", others were "in limbo" and some described being on an "uphill struggle". It was clear that no participant's journey had followed a linear path and there were ups, downs, setbacks and plateaus along the way**

- **COVID-19 has brought additional challenges for some people, but for others it has brought new opportunities and an improved sense of wellbeing**

2.1 Experiences of multiple disadvantage

Multiple disadvantage refers to anyone who has experienced two or more of the following: contact with the criminal justice system, substance use, homelessness and/or mental ill health. Nearly all (90%) of participants were either experiencing or had experienced mental ill health; 85% were or had experienced homelessness; 73% substance use; and 48% had had contact with the criminal justice system.

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[6] One of the experts by experience described moving away from multiple disadvantage as a "journey", so to get a sense of how participants were progressing, one of the first questions we asked was "where do you feel you are at on your journey?".

Figure 5: Experiences of multiple disadvantage among participants
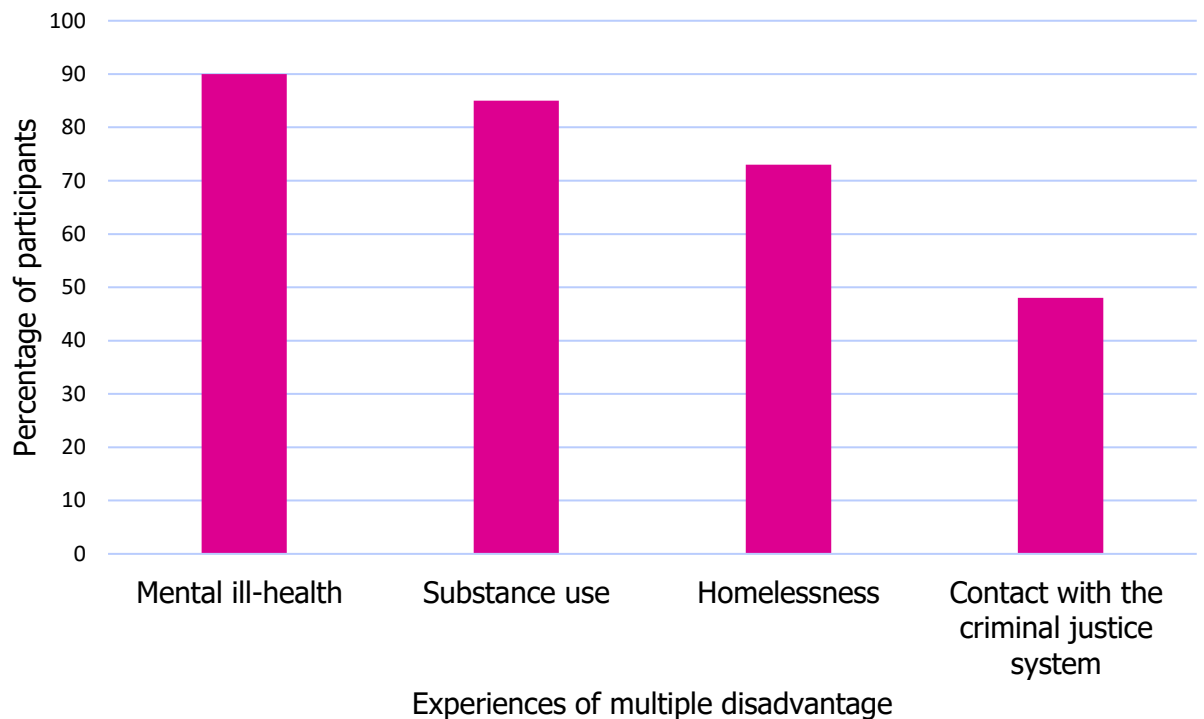
When considering the experiences of people facing multiple disadvantage it is important to note that not only can the challenges of homelessness, substance use, mental ill health and contact with the criminal justice system reinforce one another, but other issues may also feature as part of people's experience. These can include domestic or sexual abuse, involvement in sex work, loss of custody of one or more children, physical ill health and challenges with accessing welfare benefits.

The following section is spilt into three sections: on the way up, in limbo and on the edge and an uphill struggle. These categories are taken from conversations with experts by experience and from phrases used by participants in the research. It is important to note that people's experiences are not neatly categorised, and in one week or day a person may feel they have experienced all of these stages. Furthermore, some could not pinpoint where they were on their journey. This understanding that the people's journeys and recoveries are not linear is at the heart of FLLSL's work and evidence base.[xii]

2.2 On the way up

'On the way up' describes how some participants felt more stable and had been able to move away from some of the challenges of multiple disadvantage. This research was conducted during the third lockdown and this has affected the wellbeing of people in various ways; for some, COVID-19 brought additional challenges and for others it has brought opportunities. Many of the findings are reflected in research conducted by FLLSL.[xiii] Eric[7] describes how he feels he is a good place in terms of his recovery:

> "...Because it's the first time in years I actually like myself as well." (Research participant)

> "So, right now, my head is in a very positive frame of mind… I just think I come so close to death a few times … being high and that. I think it's kind of frightened me. And if I get any … I got any closer I would be dead now, know what I mean? So, I know I needed the help and I got it. I have seeked [sic] it and … it seems to be working. I don't know why, but it does … and I love waking up every day with a clear head. And I have learned that I have got to not think too far ahead and get side-tracked or have my vision clouded, by temptation or whatever"

Figure 6: Piece of reflective writing from Ethan (expert by experience)
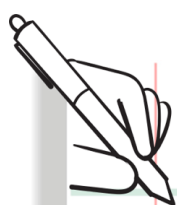
> I've been out of prison for seven months. When I was in prison I didn't know what the future held for me. I didn't know if I was going to be able to stay on the right side of the law. The day I was getting released I felt very nervous. I ended up at Lewisham Probation Office waiting for them to find me accommodation. Anyway I ended up coming to [supported accommodation through Kairos] and I feel it's the best decision I could've made for myself. I knew something had to change if I was to stay on the right path and I had to do something that would take me out of my comfort zone and now I've been here for seven months and doing quite well and I'll be moving my own place in the next few months.

[7] Participants names have been changed to protect their identity.

Participants' experiences and self-perceptions of being 'on the way up' were often framed by the difficult challenges they had faced in the past. For example, Kyran, a research participant, tells of how he felt suicidal but now can see a future for himself:

> "I had a bit of a nervous breakdown, nervous meltdown in public... A friend of mine landed in front of me and took [me] to the GP. GP sent me to A&E. And I went over to [psychiatric hospital] for the day where they did an assessment. That took a day. But at least I didn't kill myself, and that was the whole point, I was about to kill myself. And they rescued me from that and I – I couldn't face myself in the future and now I can."

For some participants experiencing mental ill health, the fact that the UK went into lockdown had a positive impact on their mental health: "My mental health is really quite … but I am in a really good place. And I have actually benefited from the outside world shutting down and it all being quiet." The pandemic provided an opportunity for some participants to get support from friends, family and support services that otherwise would not have been online. For people with mobility issues and/or mental ill health making it difficult to leave the house, lockdown has enabled more opportunities to connect online. Laura, who suffers from chronic fatigue and fibromyalgia, spoke of how lockdown has improved her wellbeing:

> "Not having to go to a place, get lost on the way and the stress of public transport and all of that is just such a good thing as well. […] So, all of that has really been fantastic. I have discovered more and more classes online which yet again I can do a lot more easily because I can learn sat on my sofa."

The COVID-19 crisis has highlighted the resilience of people experiencing multiple disadvantage and how at a time of crisis they have the skills and experience to cope. A report produced by FLLSL in 2020[xiv] details the impact of lockdown for people supported by the programme.

> "People we support already experienced isolation, limited access to services, difficulty in getting essential items before social distancing and other measures came into play and often people we support are and were coping better with the situation than we are."

2.3 In limbo and on the edge

Many participants spoke of how they were "living in limbo" or "waiting to move on". For some the pandemic had put a stop to their plans; in other cases, being in limbo was a result of waiting for the right support, for example mental health support or waiting to be moved into appropriate accommodation. For others it was lockdown and being unable to go about their normal life that had halted their recovery.[8] David describes how he feels his mental health has been on a "thin line" during the pandemic:

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[8] We use the term recovery in a broad sense to describe the move away from multiple disadvantage. We use the term journey to describe this process.

> "Through COVID it's been up and down. I have a doctor that's very good and keeping my mind active, just … so once you get a bit stagnant, if you know what I mean, it can lead to a dark world. I'll try and explain; it's a very thin line from being completely crazy and chaotic is a very thin line and I've crossed that line."

Gary, who was living in a hostel, spoke of how he was waiting to be moved into supported housing: *"So I'm kind of in limbo at the moment. I'm neither/nor."* Another participant, Sammy, who was living in an 'Everyone-In'[9] hotel also spoke of how he was waiting to move on:

> "So, I am in temporary accommodation, a hotel, at the moment. And it's not ideal. I can't get access to my computer; I can't get access to other aspects of my life that I would ordinarily have access to. And this is just dragging on, dragging on. And of course, the COVID has not helped the situation at all. So, it's just making me feel sort of isolated and depressed."

Waiting long periods for mental health support was a common finding in this research. Kim describes her long wait and challenges accessing the correct support:

> "I've been misreferred… I've been referred to the wrong place that didn't even provide the service, waiting on the waiting list all this time and then couldn't get it. And now I'm at the back of another queue… And I have … last year I was kind of really heavily using, using drugs… I was basically referred to a suicide prevention charity."

While COVID has had an impact on the length of time people have been waiting for support, and hindered people's ability to move forward, for many people long periods of waiting and the feeling of being in limbo existed prior to the pandemic. This was often due to a lack of suitable housing and long waiting lists for mental health services. This reflects research conducted by FLLSL which demonstrates how COVID-19 has exposed the pre-existing inequalities in society and our communities and within systems.

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[9] Hotel accommodation provided to people experiencing homelessness in response to COVID-19.

2.4 An uphill struggle

Some felt that they were on an "uphill struggle" or had taken some "steps back" from where they wanted to be. The challenges faced by people existed prior to the pandemic, but have been exacerbated by the pandemic.

Terrence describes how he is struggling mentally during the pandemic and being apart from his dog because the property he was in wouldn't allow dogs:

"Where I'm at the moment … I'm going up a hill, I'm going up a very steep hill and it's very difficult… How do you go up one part of a hill and there's a stumbling block where you have to go round it, so every kind of step I take, moving forward, sometimes it looks like I'm taking two steps back."
(Research participant)

"Mentally I am not in a great place with that one. I do find myself… doing strange things that I haven't done before such as sitting here and having an argument with myself, which is confusing, but I put that down to the fact that I am just in a room on my all the time… I had my dog back to keep myself … mentally stable. So, I had a companion with me. But I can't have my dog here with me because she is not allowed by the landlord."

It was apparent that the challenges people were currently experiencing were rarely new issues. Many felt that challenges with homelessness, substance use, mental ill health and the criminal justice system stemmed from deep-seated issues going back to their childhood and adolescence.

"You know, all homelessness issues, all criminal justice issues, you know, they're all kind of connected in a way, aren't they … and I'm not always sure that the time's there to kind of like untangle that trauma and properly look into that trauma, and I think that would be such a great thing if that was available and was able to be done."

Summary

This section has described the varied stages participants felt they were at during the research. No journey was the same, nor was it a linear trajectory; there were nearly always bumps and setbacks, circles and plateaux. These findings exemplify how deep-seated people's problems can be, and therefore journeys towards recovery can be unique, long and meandering. It was clear too that people sometimes found it difficult to see where to go. That was not the case for all, however; those participants who regarded themselves as "on the way up" expressed cautious optimism about their futures and had a sense

of what they wanted to achieve. In the following sections we explore the experiences of navigating support.
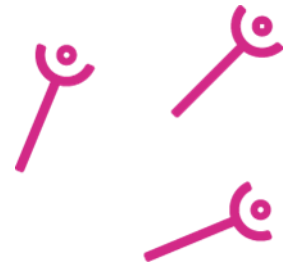
3

Understanding multiple disadvantage and support

Key Messages

- Many participants felt that the connection between the experiences of substance use, mental ill health, contact with the criminal justice system and homelessness were overlooked
- Dual diagnosis was described as a catch-22 situation where participants found it difficult to get support for co-existing mental ill health and substance use
- Mental ill health was often misunderstood and participants felt that their mental health needs were not always recognised as being "serious". In many cases participants found it difficult to ask for help and access support
- The realities of multiple disadvantage mean that people's journeys have bumps and setbacks; however, the way services are designed in many cases does not reflect this reality
- Where people were seen holistically as a person rather than a "collection of issues", the support they received and relationships built often led to better outcomes

3.1 The bigger picture and the whole person

The following section details the experience of multiple disadvantage and the challenges people experiencing multiple disadvantage can face in getting appropriate and timely support. This section first describes the interconnectivity of such issues and the impact that overlooking the bigger picture and the whole person can have on people's wellbeing. These finding show the importance of programmes such as FLLSL that focus on the bigger picture.

The interconnection of needs

Issues associated with homelessness, mental ill health, substance use and contact with the criminal justice system are often interconnected and challenges with one issue can often trigger issues in other areas. This reality is at the core of FLLSL programmes and is reiterated across the FLLSL evidence base, including the system map.

During workshop sessions held as part of the peer research with experts by experience, we repeatedly discussed how all these issues were connected, but that services often overlook this and obscure the bigger picture of people's support needs. For example, challenges with mental ill health can mean people use substances as a coping mechanism, which can turn into a longer-term dependency. Similarly, housing-related challenges can lead to substance use as a coping mechanism.

Dan describes the connection between his mental health and homelessness and how he felt the housing issues he was experiencing led to psychosis:

> *"The housing was more important to me than heroin, but heroin was available than housing."*
> (Research participant)

> *"I think the main trigger for psychosis was my rough sleeping, homelessness and just complete lack of fixed abode and standard of living… And when I came to rough sleeping, I ended up – before I had UC [universal credit] and I panhandled. But it wasn't enough to keep feeding me. So, I would shoplift sandwiches from Tesco's and eat that. I didn't think I would ever be a shoplifter but circumstances happen."*

Lily describes how she feels she needs joined-up care to help her with her eating disorder and addiction:

> *"I think what's happening now is my addiction has turned into an … eating disorder, which I have a history of as well. I'm, well, I'm not I think, I now, I am behaving anorexic at the moment and I would like, I really want somebody with joined-up thinking rather than, because my key worker knows and he's wonderful for the alcohol, but we both agree we want somebody who has got joined-up thinking for my care."*

This example illustrates the interconnectivity of issues, the need for joined-up, coordinated support to reflect this and for support to see a person as a whole. While some participants spoke of how these connected issues were recognised, and support services could see their bigger picture, many felt that this was not the case. Participants described how they have to go to a different service for each of their separate issues and there is little or no coordination between them. This left some participants feeling as if they were a "list of issues" rather than a human being. This finding is not uncommon and is echoed in the literature review published as part of the FLLSL programme:

"Service fragmentation is at the root of poor responses to multiple needs. Broken up into different departments and services, each with their own systems, performance targets and governance arrangements, state services often fail to support people with multiple needs." (McCarthy et al, 2020: 7)[xv]

Kirsty's experience below illustrates the consequences of not looking at the whole person. In this instance, this participant's health issues were overlooked because of the challenges she was having with substance use.

Case study

Kirsty – Looking at the whole story

"I've recently changed doctors as well because it was picked up that I had a thyroid problem before I went into detox … and they wouldn't do anything about that [my addiction] until I was at least on some medication. And the doctors I was with, who are right next door to the recovery house as well … they kept saying there's nothing wrong with your thyroid, they kept sending the bloods back and then they phoned up and when the doctors from (drug and alcohol detoxification unit) phoned them up and said, 'There is a problem with her thyroid. Look at the bloods again', they admitted that because they knew that I was a substance misuser and alcoholic, they only looked at the liver and kidney profile and didn't look at the whole profile. And I don't know whether … that, I mean I just was so shocked really that they would do that."

Figure 7: Piece of reflective writing from Trevor (expert by experience)
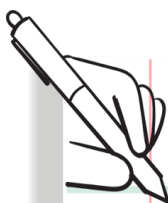
I've been using drugs on and off in my life for the past 30 years. I've also been in and out of prison quite a few times. So my life hasn't been a brilliant journey. I'm 55 years of age and out of those 55 years at least 15 years has been in prison. I can't really say it is the drugs but I think they played a part in me going in that direction. I lost my job and also my flat and that is because I was using drugs. But I can honestly say I am in a better place. I have been free from drugs and alcohol for 15 months now and I have to admit I feel great. But my journey doesn't stop here. It is an everlasting journey that I must continue to overcome. I have friends and family to support me. I also get plenty of support from Groundswell staff who are brilliant to work with. So that's it really, my journey on the right road is still ongoing. Thank you for listening.

The chicken and egg of dual diagnosis

The failure to see the whole person and the other challenges people were experiencing was especially true for those with substance use issues. Many participants spoke of the connection between substance use and trauma in childhood, adolescence and/or in adulthood; however, it was felt that this connection is not always recognised by services and that some unhelpful attitudes towards addiction still perpetuate. For instance, many people felt that support services, and wider society, often reduced all issues to substance use.

> "It was, because I just, I didn't feel that they were fully appreciating that the whole, everything was connected and that the alcohol misuse was a part of that kind of combination of things… I felt like I was being judged for the alcohol part of it, but I wasn't being judged for the mental health part of it, and they couldn't see the connection, they didn't make the connection between the two. So, that, that was disappointing."

This appeared to be, in part, due to deep-seated beliefs about people who use substances that still exist within society and support services. These beliefs shape how services are run and designed.

> "I think a lot of people are stuck in the mentality where they think addiction's a moral defect as opposed to a … social issue, or if you want to use like the 12 Step model, a disease issue or a mental health problem, however you'd like to phrase it, obsession, disorder, whatnot. So, yeah, I think, I think it's just the … the framework in which we discuss it is just a bit antiquated."

Both participants and experts by experience felt that their identity was often centred around their substance use rather than the many other aspects of their identity. Nathan tells of how he feels defined by his drug use, but that his drug use is only a small part of who he is:

Related to this, participants and experts by experience alike felt that there was an underlying attitude within the system and among professionals that if people had challenges with substance use it was self-inflicted and therefore entirely their fault, whereas people often use substances to meet an unmet mental health need. As a result of these

> "My drug use doesn't define me, Yeah, I use heroin, Some days it's a small part, some days it's a big part, some days not part of me at all. It doesn't define who I am. I am a person. I am no different to anyone else, I just want the same as everyone else. Just to be treated with respect…"(Research participant)

attitudes, people may not receive the support they need. This is reflected in a forthcoming report on dual diagnosis by FLLSL[xvi] and by this participant:

> *"I've only ever told him [GP] once that I was using, and when I told him that, found out later that that had actually worked against me in getting some funding for some service because they won't treat you if you're using, and I was using so I couldn't get any help. So, you know, what came first, the chicken or the egg?"*

Furthermore, judgmental attitudes can hinder the ability for trusting relationships to develop. As identified in the literature review, *"non-judgemental attitudes by staff were identified by both people accessing services and practitioners as being important for building trust and successful relationships"* (McCarthy et al, 2020: 7).

It is not uncommon for people with co-existing mental ill health and substance use to be passed between services or unable to access them at all. There can be conflicting eligibility thresholds which do not reflect the realities of living with dual diagnosis. The interconnection between issues highlights how for many there is often little or no distinction, for example, between mental ill health and substance use (see FLLSL's forthcoming report on dual diagnosis). These challenges accessing support for people with dual diagnosis have existed and been well documented for several years (Pycroft and Green, 2016) [xvii]. However, it appears that Pycroft and Green's (2016: 148) assertion that there is a *"great deal still to be pessimistic about with respect to developments in addressing dual diagnosis"* still runs true to this day. FLLSL is working with partners locally to ensure national guidance on co-occurring mental ill health and substance use is followed locally, as well as working with people with lived experience to co-produce a systems pilot that improves local access to substance use services (see submission to Dame Carole Black's review[xviii]).

When the dots join

When connected challenges are recognised, this makes a difference to support received and the wellbeing of people experiencing multiple disadvantage. Some of the outcomes for people supported in this way are evidenced in the FLLSL Annual Review (2020).

The support received at the local criminal justice support service – the Beth Centre[10] – enabled Rachel to get all her interconnected issues addressed, coordinated by a key worker:

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[10] The Beth Centre is a safe confidential space providing expert support for women at risk of, or affected by the criminal justice system living in Lambeth. They aim to reduce contact with the criminal justice system; increase positive family relationships and increase the use of community sentences, rather than custody, for women.

> "And I feel like my mental health and my substance misuse is both connected. And the 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."

Having access to one service that could recognise and respond to multiple needs was seen as highly beneficial by many participants. Ahmed explained the support he was receiving from a drug and alcohol service called The Harbour:[11]

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

The extent to which services and people within them can see the whole person can impact the extent to which they can understand a person's context, the relationships that are built and the quality of the support they can give. This consequently has an impact on the wellbeing and recovery of people facing multiple disadvantage. Where someone has been treated in a person-led way, rather than a problem, the support they have received and the relationships they have built are often quite different. However, participants recognised that some services have challenges around flexibility and that the ways services are designed means that they can often only offer support for one issue. As a result of this, services can find it difficult to work collaboratively to support people with the multiple issues they are facing.

> "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." (Research participant)

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[11] The Harbour is a drug and alcohol support service in Lambeth for people looking to sustain their recovery.

Case study

Jo-Jo – person-led support: consistency, patience, and flexibility

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. Her link worker describes some of the challenges she has experienced:

"And the difficulty is that the relationship – even though it's a highly toxic and abusive relationship – he essentially holds a lot over her because he helps to feed her drug and alcohol habit. So, the difficulty is trying to separate the two. Trying to get her away from him, without putting her more at risk."

Jo-Jo's link worker referred her to the MARAC (Multi Agency Risk Assessment Committee) 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."

After undergoing a lengthy assessment and the funding application for rehab, Jo-Jo went into a rehab outside London for seven months. Jo-Jo's link worker liaised with housing and all of the professionals supporting her encouraged her to consider rehousing outside London due to the high risks of her returning. Jo-Jo decided that she did want to return to London and her local authority agreed they had a duty to house her. A suitable address was agreed with her and the council, but when she arrived she realised it was not safe. Jo-Jo was offered temporary housing in a different borough but she hasn't been seen for several weeks. There has been a pattern of Jo-Jo going missing. Her link worker talks about this and what has made their relationship work:

"Consistency, patience and flexibility, I think. Until she is ready or feels able to sort of step away from the relationship. I don't know when that will be. It will only be when she feels ready or able to do so... And she has to make that decision. And what we can do as services is just ensure that we are all there, ready for when she does make that decision."

Up, down and rock bottom

Many support services are designed in a linear way where someone comes with an issue, they are given a certain amount of support, and after that support is finished, they are expected to be in a 'better place' and move on and not face any subsequent challenges. However, as explained in this research, the reality is quite different.

Experts by experience explained that "*relapse is part of recovery*" and that "*people should not be punished if that happens*". 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. Participants felt that many support services, and the professionals working in them, need to understand and adapt to the bumpy road people experience on their journey away from multiple disadvantage.

This assumption that people will have recovered after a particular period of time means that there are often few options if further support is needed. Judy explains the challenges of getting support again:

"The expectations of 'oh, this person needs to have moved on from this level of support of onto this level of recovery' … And trying to realise that relapse is part of the process of recovery… And not necessarily just some sort of washing my hands of a person because they have fallen back into old habits…" (Research participant)

> *"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."*

Such challenges often mean people must "start again" or reach "rock bottom" to be able to access support again. After being homeless previously, Flo describes how they deliberately got themselves evicted and became homeless again as they were unable to get support for an issue they had in their flat, "*so I deliberately got evicted from that to get back into the system to get back out and try to get it right the second time*". Flo felt that they needed to do something which sabotaged their short-term wellbeing in order to access appropriate longer-term support. Some participants felt that certain services were not designed in a way to support a person's wellbeing and recovery, and felt strongly that they are set up for people to fail and/or to face ongoing challenges.

> *"But what I got to find out was, when you are actively sex working and doing drugs, that was an organisation – it's like they want to keep you in that position. […] So once I got clean, they didn't want nothing*

to do with me anymore. They encourage you to get into … to find you accommodation, encourage you to seek treatment for your alcoholism or substance misuse. But once you go to treatment and get better, that's it – you can no longer access their service. Whereas the Spires, they will deal with you until you feel fit."

This echoes Gillian's experience. It was not until her situation deteriorated that Gillian got the support she needed. She also explains how she thinks support services wanted her to 'fail'.

"I got really, really, unwell to the point where I was basically nearly hospitalised and was in a bad place, they put me into housing on my own. So why was that acceptable? So now I am actually not in a bad state, I am actually stable and I am not drinking like I did before and I actually had support around me, but you are not going to help me."

"It's very hard to concentrate, you know. Like when you have just come out of 30 years of abuse, your concentrations level and your memory and everything is just completely … your wires are all crossed. Do you know what I mean? Somebody says it's like the brain has just frosted up and you are trying to defrost it and get all the shit out. So yeah, I am just taking it one day at a time really. Can't really think too far ahead" (Research participant)

"They put you in places for you to fail. That is what I have noticed. They want you to fail. They want you to keep doing the continuous circle."

Participants highlighted how many services are time bound and there is little support to help people in terms of sustaining recovery and wellbeing. Support is often available for a specific length of time and people are expected to have their issue resolved within that time. Funding cuts have put restrictions on the amount of time people can receive support, which means many cases are closed perhaps earlier than they should be. Life transitions, for example, moving from one support to another or from one living situation to another, can be a critical point and people need to be supported at these times.

Chantel shares her experience;

> *"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… So, I kind of felt that after I'd been to [recovery service] and did the community, I didn't have any support after that, and then that's when it kind of spiralled out of control again."*

Services that are open and not time limited are key to the ongoing recovery of participants:

> *"It's good because it's very person specific, we had both the groups, so a lot of peer support. It's very open, it's really wonderful that you can be at any stage. You can be using, not using, whatever, any stage, and there's still loads of support around. It's really wonderful."*

Transitions are a key point in a person's journey; however, because of the time-bound nature of much service provision, support is not always there to help people with their transitions. Communication and coordination between agencies and the continuity of trusting and meaningful relationships between practitioners and the people they support are key to ensuring transitions are smooth and supported. Reflecting this, FLLSL looks to support people in ways that recognise journeys are not linear. FLLSL has piloted models and approaches focused on transitions, including Critical Time Intervention (CTI).[12]

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[12] Critical Time Intervention (CTI) is a time-limited evidence-based practice that mobilises support for society's most vulnerable individuals during periods of transition: https://www.criticaltime.org/cti-model/.

Case study

Darren – relationships and transitions

Darren (39) has been working with FLLSL since 2017 after he was referred by his local drug service. Darren's goals when referred were to clear his rent arrears, move out of the borough he currently lives in and get his driving licence. As time went on Darren identified that his dream was to buy a camper van to travel the world and become an actor, starting as an extra.

Darren was arrested in April 2019 and remanded in prison after a violent incident at the hostel where he was living. During this time in prison, his FLLSL link worker continued to visit him and supported him with his mental health, accessing a prison GP to get his HIV medication and to prepare him for trial.

FLLSL was informed that Darren would not be offered accommodation if he was released from prison because of the violent nature of the attack at the hostel. Darren was released from prison in September 2019 on a suspended sentence. He was met by his FLLSL link worker and taken to the housing office where he was told he was not eligible for temporary accommodation, but he was placed in an overnight shelter.

Darren was eventually referred to St. Mungo's who agreed to work with him alongside FLLSL. He was offered supported housing which Darren did not want due to his previous experiences of violence in supported accommodation. FLLSL advocated for Darren to be accepted for private rented accommodation and also supported him to apply for universal credit. Darren's peer link worker helped him to identify his goals, including finding an acting course. Darren spoke of how the relationship with his link worker and support provided have been key in helping him move forward.

The many faces of mental health

In this research it was clear that people often felt they needed to reach crisis point to get support. This relates to a wider issue – that participants felt they didn't 'appear' to look like someone who needed help: *"And if you don't present and talk in a certain way and relate yourself in a certain way they almost don't see it. They don't understand you."* Philip explained how this made him feel: *"It's hard to … it compounds the notion that there is no connection [between people accessing support and support staff]."*

In this way the system is rigid and is not set up to consider the varied ways in which issues can present in people differently (see systems map). People can be forced to present themselves in certain ways so they can be recognised as someone in need. Some people described how they physically changed their appearance to look like 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."*

> *"But it always felt to me that unless you were literally frothing at the mouth and sort of like completely doolally at the time... So, to be able to access that support, it wasn't always that necessarily that straightforward or that easy sort of thing... And it felt a little bit sort of like, what specifically do you want from us because from our perspective you don't look as or seem as if you really need that much support. So, it's kind of that aspect of it that I found awkward and difficult."* (Research participant)

For others, a change in their behaviour was more subtle, for example, talking a certain way or using a certain type of language. Participants spoke of their frustration when they felt that they were in need of support, but this need was not identified by services. This affects people's motivations to seek support again and can create distrust of the system.

Participants commonly spoke of a disjunction between how they felt and how services perceived their situation. This suggests that perhaps the criteria by which services determine need are not reflective of people's lived realities, notably how multiple disadvantage can present itself and the ups and downs of people's journeys. In addition to this, there perhaps needs to be a better understanding among services and people within them about how challenges manifest differently in people. If the system met people where they were, recognised them as a person and was truly personalised, then people would not feel as if they need to present in certain ways to access help. This approach is very ineffective because it often requires people to reach crisis point before their needs are taken seriously.

Asking for help

This research found that people can find it difficult to ask for help. This finding is reflected in FLLSL's submission to Dame Carol Black's review, which highlights the need for accessible information about what help is available and how to access it. Asking for help is also difficult when people have feelings of low self-worth. People also spoke of how they felt embarrassed to ask for help: "*It's sometimes embarrassing to look like you can't cope so you front to others.*" Stella adds;

> "*I find it, like … a bit embarrassing and a bit kind of feeling like you brought this upon yourself, you shouldn't need to … take up people's valuable time by moaning about a situation that you kind of got yourself into. Like, I understand it's much more complex than that, of course, and that's why I do ask for help, but, yeah, it's not easy, you know ... by any means.*"

As a result of this embarrassment, people may not ask for help until their situation deteriorates. The fact that people can feel embarrassed highlights the stigma and shame that is still associated with multiple disadvantage. Breaking down stigma and shame will enable people to feel comfortable about getting the support they need. Jason describes how liberating it can be to talk to people without shame or stigma:

> "*There is that stigma associated with alcoholism, which isn't particularly helpful for people who are alcoholics. And the perspective that I have gained over the last few weeks, having come to terms with the fact that, yes, I am an alcoholic. And then having spoken to and met with and had private conversations with people that have addictions to all sorts of things, not alcohol, I completely understand. I am free to have a conversation with them about addiction, in a way that maybe nobody else can... So, I have seen this … this process has been hugely enriching for me as a person. It's just added another string to my string of experience. So, I am enormously grateful and*

really, really, quite excited about finding out something I didn't know. That is... I have got a new view."

We found that those who have had bad experiences with services before found it difficult to ask for help. As discussed in the next section, some people had tried to get support many times and been unsuccessful, which resulted in them wanting to give up. It was also the case that people who have taken on a caring role found it hard to ask for the support they need:

"All my life I have looked after myself and younger brothers. I have never had to rely on others and now I feel so weak and down but because I have never had to ask for help it's really hard for me to let myself and tell myself that it's okay to need others' help."

The opportunity to participate in groups or seek support from others with lived experience removes some of these barriers: this principle lies at the heart of the FLLSL programme delivery. We discuss the value of peer support in more detail in chapter 4.

3.2 Hoops, circles and tick boxes

Being passed around

Participants spoke of how they felt as if they were being passed around between services:

"There's essentially never an outcome. Like even when, so we have back and forth and then when I do get through to them, they go, 'Yeah, just to let you know, I'm going to chase that up for you,' and then I don't know what they do after that, whether they send someone an email and whatnot, but it's just, no matter whether I speak to like my doctors or the psychiatrist's office or an intermediary, like trusts or whoever's giving the funding or whatever, it's just like a never-ending passing of the buck, people saying that they're going to chase people but just, I can't help but feel that it's just so underfunded and everyone's just basically passing me around just so no one has to admit that their e services aren't available."

Reliability and trustworthiness are key in building relationships. If people cannot trust someone with the 'small' things, for instance, calling them at a set time, it will be difficult to trust them with their 'bigger' things.

"He made an appointment for me to go into the office about two weeks ago and for a certain time. I get there for the appointment and the staff in the building are looking for him and they can't find him… He says he will phone on a certain day, at a certain time, and that phone call didn't materialise, [that] sort of thing."

Participants also spoke of how it was difficult to get the support they needed and build relationships because of high staff turnover and other capacity issues. Austerity measures have had a severe impact on staffing and resources, which affects the support services can offer people. Thresholds for mental health support have been raised and there are long waiting lists for treatment.

"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."

The feeling of being passed around points to a system that is fragmented, limited in resources and lacking clear lines of accountability. Austerity has meant cuts to funding and capacity; this puts pressure on support workers who are time poor and stretched, which in turn impacts on their relationships with the people they support and can make it impossible to work in a person-led way. Relationships and trust are identified as a key element of support provided by FLLSL because the FL approach allows for capacity to provide holistic wraparound support.

Ticking a box

A common finding in this research was the idea that people need to fit certain criteria to get support; participants often referred to this as "ticking a box". Within this research and wider FLLSL evidence including systems mapping, we found high thresholds for accessing support and the challenges people had in meeting these thresholds. To start a conversation on this we asked participants whether they agreed or disagreed with the statement: "I did not have to fit criteria to get support."

"I would say that is 110% wrong. You actually do have to fit very specific criteria. And if you are … a bit outside the box or you don't appear to be unwell or to need help, then you can dream, it's not going to happen. End of."

Tina describes her experience of trying to "meet the criteria" for mental health support – she felt that the fact that she was living in a night shelter should have been enough evidence:

"You have met the criteria because of this and this. There was a point where I am living in a night shelter, what criteria is there left for me to meet? What do I need to physically do to meet your criteria now? Like now I am living in a night shelter, why is there no support for this?"

"It's very open, it's really wonderful that you can be at any stage, you can be using, not using, whatever, any stage, and there's still loads of support around. It's really wonderful." (Research participant)

Fiona tells us of the criteria that needed to be met and how despite meeting them people were often not believed:

"So even going to housing, and trying to figure out, even if you meet a criteria [sic], homelessness, coming out of prison, whatever your

situation might be, they don't believe you. <Laughs> Go to this place, go to that place, you might end up going to 10 different places before you end back where you were supposed to be."

Not all participants felt they needed to fit criteria to get support. Participants shared examples of charities which they described as having an "open door policy" where there was no or little criteria in terms of getting support and that people could be at "any stage of their journey".

Getting online

One challenge that participants faced was access to technology and the necessary skills to access online appointments and other services to support their wellbeing. The COVID-19 pandemic made a lack of access to technology even more significant because many services have moved to online access only. Jane describes how multiple pieces of technology are needed to renew a freedom pass:
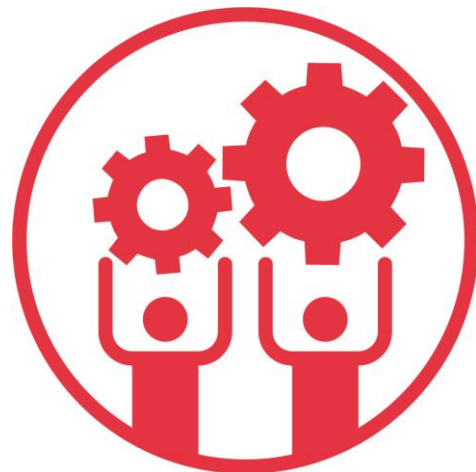
"I got a letter to say that my Freedom Pass needed renewing and the letter gave you a link to access and then you need to fill out this renewal form online. And then you had to attach and scan supporting evidence with that. Now while you are assuming that everybody has a) got a laptop, b) got a scanner, c) got internet in their house… I just thought to myself … what makes you think that I have got broadband, that I have got a scanner, I have a laptop."

When asked why accessing services had become more difficult, Dawit explained: *"I struggle with internet and things like that really. I can't… I don't have a laptop at the moment, so I am struggling with myself really."* Despite having the technology and being able to use virtual meeting tools, Sadie missed a meeting about her housing situation because she could not download the relevant software onto her phone. The services were unable to accommodate her needs and the meeting took place without her.

"I have tried doing the Zoom meeting on my phone, and my first experience was … basically partly to do with the connection, it was a bit bitty and breaking up a bit. And so, my experience of doing the online thing at the moment because I don't have access to my computer has been a little bit … not very good experience to be quite honest."

For some, regardless of having the technology and skills to attend appointments and meetings online, their mental health was so poor that they were unable to attend online appointments. In a world that is becoming increasingly digital it is important that there are ways people can still access the support they need and be involved in decisions about their wellbeing and journey. FLLSL have been working with people they support as well as EBEs and ambassadors to provide the necessary technology during the pandemic;

further research is being conducted into this and will be published at a later date.

Going nowhere and giving up

The challenges people had experienced in navigating the system and being unable to get the support they needed mean that some people just felt it was not worth trying. This connects to the FLLSL philosophy that the *"system is hard to reach rather than people being hard to reach"*. Participants described how they weighed up the effort they needed to put in to get support against the likelihood of getting support and felt that it was not worth their time or energy.
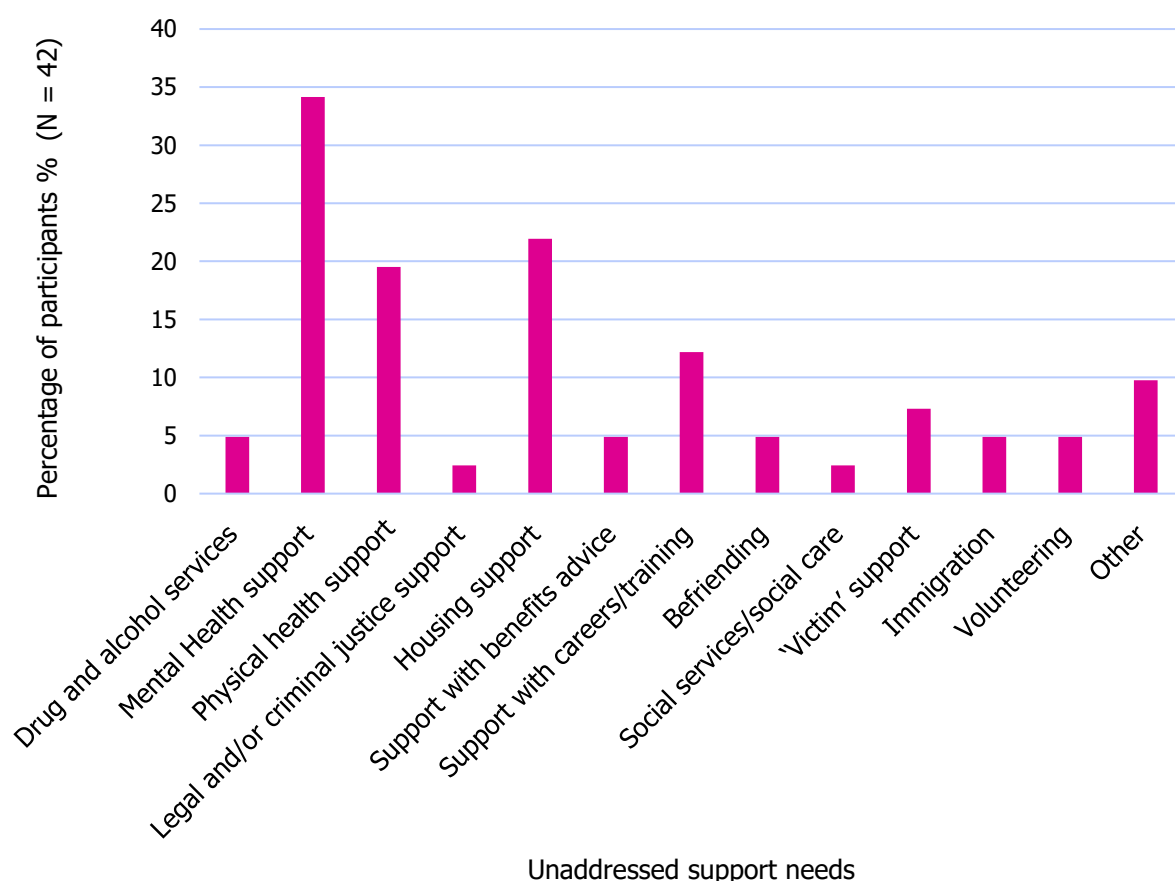
"But there's some things I might sometimes look into and I might think, that's probably going to take, the asking for the help, the hoops they're going to make me jump through, the games I'm going to have to play, still quite likely going to get a negative outcome, I need to sort of step back and think, well, this one isn't worth it." (Research participant)

Adio spoke of how the lack of a positive outcome after waiting for support, combined with repeatedly telling their story made them feel that they didn't want to continue trying to get support, *"like just repeatedly telling your story, you know, repeatedly being asked inane questions, thoughtless questions"*. Long waiting lists for mental health, substance use and/or housing support and no outcome or progress can make people feel like they want to give up.

"I have been on the waiting list for that for maybe three years. […] And you are just like ... what the point? Waiting and waiting and waiting. And the last time I called the people at [support service] the lady answered the phone, she said, 'Oh we are struggling now,' and she just hung up … and it's like if you're struggling and you are sitting there just taking phone calls, because of the pandemic you are struggling, what do you think about the people who are trying to access your help? So that completely put me off."

The challenges people face in navigating the system can mean people give up seeking the support they need. Long periods of waiting without an outcome can have an impact on people's wellbeing. Challenges accessing mental health and housing support were particularly common. As the graph details below, we asked participants if they had any needs which they felt were not being met.

Figure 8: Self-reported unaddressed support needs

Y-axis: Percentage of participants % (N = 42)

X-axis categories: Drug and alcohol services, Mental Health support, Physical health support, Legal and/or criminal justice support, Housing support, Support with benefits advice, Support with careers/training, Befriending, Social services/social care, 'Victim' support, Immigration, Volunteering, Other

Unaddressed support needs

Seeking support and not having any outcome from it can be damaging; *"I just feel like it's an actually futile activity. You go for an assessment to get a service and then the service never appears, so you just feel like you're getting your hopes up for nothing."* People who had experienced challenges accessing support felt frustrated when they saw others moving on:

> *"You see other people kind of waltzing through the system and coming out the other side and living a new life, you know what I mean, and I envy that. And I think that that's like, you know … I don't know if it's a wasted opportunity, if it's me, or if it's the system and it's a combination of both."*

This quote raises a few important points. It illustrates that the system can work well for people; however, it suggests that the system does not work well for everyone and that certain people can be left behind. Such experiences can cause people to blame themselves where things do not work out for them or they do not see any progression.

The following story is based on a combination of empathy mapping[13] and story boarding exercises undertaken conducted by the experts by experience group. We created a story based on a fictional character called Fred, but the group brought elements of their own experience into Fred's story. We all grew very attached to Fred and as a group we wanted this story to illustrate

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[13] An empathy map is a collaborative visualisation used to articulate what we know about a particular group of people. In empathy mapping groups think about what a person might think, do, say and feel.

the challenges people can have, but also how through the right support people can overcome these challenges.

Empathy Mapping

Fred describes himself has having dual ethnicity. He has long dreadlocks of which he is very proud and he loves eating seafood, travelling, and reading. Fred was studying at university when he tragically lost both of his parents. The impact on his mental health was severe and led to him becoming homeless. Fred was placed in a hostel and he found himself self-medicating with substances. Many of the other residents were also using and he was not able to form any meaningful friendships or trust anybody. Fred was fearful for his safety, so he did not sleep at the hostel which caused issues with the hostel team.

Fred felt like the practitioners at the hostel did not care about his situation and were just there for their pay-cheque. He found it hard to talk to them about his mental health – he was constantly threatened that he would be evicted because he was sleeping out. Fred faced more stress when he could not produce any documents proving his local area connection or any ID documents for claiming benefits. The pressure made things worse, and Fred was sectioned under the Mental Health Act. Fred got some help and support and he went for bereavement counselling; he was then discharged and went back into the hostel.

When he returned to the hostel Fred started working with a new keyworker who was proactive and supportive. She encouraged him to attend CV writing courses and to start volunteering at a local bakery (a social enterprise) because Fred eventually wants to become a chef. Fred gained the documents he needed to prove his ID and his local area connection, and his keyworker is supporting him to apply for social housing. Fred has met a supportive partner, and this has been very positive for him. He has also re-established contact with his extended family.

Fred is now looking for full time work, but many jobs are offering zero hours contracts which would not be suitable while he is still living in a hostel with high service charges. He is also finding it hard to find full-time work because he must explain the gaps in his CV and inform employers about his mental health condition. Fred suspects his long dreadlocks also play a role and he sometimes feels pressured by society to deny his culture and heritage. Fred has a second interview for a full-time job and he is more confident with applying and attending interviews. Although he still faces challenges, he is feeling much more hopeful about his future…

Summary

These findings exemplify the challenges people can face accessing support. Many participants were unable to get support or waited long periods and this had a detrimental impact on their wellbeing. For some, the stress and effort of being able to get the support was not worth the investment. Participants described a rigid system that did not seem to recognise the reality of their challenges and the interconnection between them. However, where services and individuals saw the person, rather than a series of separate issues, this had a positive impact on relationships between support workers and the people they are supporting, and enabled people to move forward.

This chapter also illustrates how there are still significant pockets of the system that are reinforced by out-dated and unhelpful stereotypes about multiple disadvantage. Participants described how attitudes with a narrow view on mental health and addiction meant that some people were not able to receive the support they needed. People need joined up support to help them from one chapter of their life to the next; however, during times of transition there is often a gap in support which people can fall through. The descriptions of people's journeys and other evidence from this research highlight that policy and practice need to avoid seeing the journey people follow as a linear path.
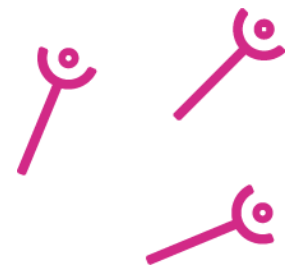
4

Creating better services and learning from experiences

Key Messages

- **Being listened to and given 'choice' are important for people's wellbeing and recovery. When support services judge the choices people make this can have a negative impact on the progress a person makes**
- **As part of their journey people need to navigate challenging relationships. Building trusting and meaningful relationships are key to the wellbeing of people facing multiple disadvantage**
- **The power of shared experience, whether it is peer support groups, employing people with lived experience, involving people with experience of multiple disadvantage in designing services or contributing towards systems change has the potential to be transformative**
- **Informed approaches can have a significant impact on relationships built, attitudes of those who work in services and the environment that services operate in**

4.1 Being heard and in control

An important theme in this research was about being heard and in control – by this we mean the extent to which people felt listened to and the power they have over the support they receive. Participants tended to use the words 'control' and 'choice' rather than power to describe decisions about the support they received. The power dynamic between professionals and people accessing support was a theme that repeatedly emerged from conversations with participants.

Listening

When participants felt listened to by professionals working in the system this made a big difference to their outcomes and it fostered stronger relationships. Within these relationships, 'small things' could make a huge difference.

"So, somebody sitting across from you taking notes and somebody sitting besides [sic] you taking notes are two totally different things where you can kind of see what's going on and like you feel a lot more kind of empowered to be able to make decisions and you feel like you're really the person wants the answers that you're actually giving them, you know, so they actually want to have that discussion with you … rather than just that's their job."

Being listened to and understood by people providing support is key to people's sense of control and empowerment. Marcus, who had recently been released from prison, described how he was supported to integrate with others upon his release and how listening was vital to this. The importance of this is also reiterated in Darren's experience of the transition from prison (see case study Darren).

> *"They sat down and talk, took notes. And actually, listened and they said … yeah, talk and talk and they haven't been where we have been."* (Research participant)

"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".

Where services cannot provide support or help a person's situation, being listened to was still important for that person's wellbeing and sense of self-worth: *"I do think that there's something about being listened to, and even if they can't help you, just a bit of respect in that, even if their workload is overbearing."* On the other hand, not being listened to can have a detrimental impact on the relationships and trust between people and the professionals supporting them.

"When I had a diagnosis of what my mental health was, she got in touch with the psychiatrist and in a three-quarter hour phone call, he diagnosed me with this, that and the other. Anyway, he sent a letter and the letter wasn't even describing me. And I phoned her up and I said this [unclear] been diagnosed on this, he's put down that I was suspended from school – I was never suspended from school. He put down that I have got an issue with switching on and off light switches – I don't have that issue. I check the door, but never the light switches. So he was saying I was pregnant at 15; I said I was 16 when I was pregnant, I had left school."

Simon feels that there has been an improvement in recent years in the homelessness sector:

"You were homeless and you get what you're given, and that's it, and be grateful. But I think that kind of thinking has changed. Well, obviously it has, because I've got what I want this time, so I could see a big change in the industry and they're obviously listening more to their clients and not just deciding what's best for their client."

He then describes how he was given a choice over where he was going to move to:

"She looks you in the eye and she explains what's possible. That's the kind of person I like to … tell me what is possible, tell me what's available, and then I can make a choice. And she said to me, 'That's what's available. What do you want?' And I said, 'I think I should go with the over-55s.' And she said, 'I think you've made the right choice.' So I feel comfortable, 'cause she let me make the choice. She didn't decide it for me. So if I'm not happy there I've got no one to blame but myself."

Figure 9: Piece of reflective writing from Stephan Morrison (Groundswell researcher)

"Having spoken to quite a few people conducting interviews on behalf of Fulfilling Lives, I found participants tended to be more likely to display a positive mental attitude if they felt listened to, heard and valued by the services that were supporting them compared to a more fragmented and distorted perception of reality from those who didn't.

It's one thing to talk about making changes to the current system and including people in the decisions about the care they receive, but I think it's equally important to learn to understand the reasons why someone is experiencing multiple disadvantage in the first place.

Helping paint a picture of that individual's history to better understand where they have come from, while showing them empathy, tolerance, forgiveness and acceptance as they take those first early steps, and often for the first time, onto that precarious and difficult path to recovery can sometimes be the difference between success and failure.

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."

Choice

Choice, or lack of choice, was a common theme that participants spoke about and is also reflected in FLLSL's submission to Dame Carole Black's review (2021). Many described how the control and choice they were given varied depending on the situation:

> "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."

Perceptions of choice can vary between people with multiple disadvantage and those who support them. Participants spoke of times when they did not have a choice or their choices were limited. Participants spoke of how they felt that some practitioners believe that people do have a choice, but do not necessarily make the 'right' one. Walter describes how he was told that he made bad choices:

> "I was told I made bad choices all the time: 'You keep making a bad choice.' Well then, I say… I made a choice, how can I improve it? But at the time it wasn't about choice to me. But to them it was about choice."

The idea that people have a choice was reported by participants to be a common misconception among some people working in services:

> "I'd say the number one misconception across all services is that it's a choice, at some point in your life there was a choice and there was a path to go left or right and you chose to go right. That's so ridiculously naïve."

On the other hand, where participants felt empowered to make choices and exert control their situation, this was helpful for their recovery: "With my addiction counselling I am told that it is my choice. So, yes ... to a certain degree, yes, it is my fault. But it's not done in such a way that I feel at fault." There is an important distinction between blaming someone for their situation and the choices they have made and supporting them to feel empowered over the choices they have.

The extent to which people feel they are listened to and have control affects the expectations set and whether people feel they have a say over what 'success' looks like to them. In this research, we found that targets and expectations were often set by commissioners, services and staff within them rather than people themselves. This research reveals that there is often more 'value' associated with some choices over others and that support practitioners can attach their own personal value judgements on the choices others make. Imposing these value judgments on others is not helpful for people facing multiple disadvantage. These values can often stem from targets and outcomes required by commissioners. In addition to this, participants spoke of when they had felt patronised by services in part due to perceptions that practitioners in services may have about people experiencing multiple disadvantage and the 'choices' they make. Time taken to build trust and develop a relationship is the foundation of a person-led

approach; this then allows services to understand a person's needs and desires, what motivates them and their context, therefore supporting them to make the 'best' choices for *them*.

Case study

Kemi - Choice

"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. Or you know … a urine test every time I walk in the building. Whereas my present worker, I haven't done a urine test in a long time…. I was like I have got to get off it, I have got to get off it. And I would you know … [unclear] my script and get off it for a few months, you know. And then just you know … relapse, relapse, there was just this constant cycle. Whereas now I am like … I am not harming anybody. So, my drug use ... is my personal choice. And, like, I couldn't say that to previous keyworkers. But you know, with this current one I can."

Kemi's experience sparked a lively discussion among the experts by experience. Initially upon reading this, some of the group were surprised that Kemi's drug use had reduced when his key worker stopped testing him. Typically, services are commissioned to conduct regular drug tests – this is reflective of the medicalised system and approach to addiction. This led to a conversation in which the group discussed how people can be punished for relapsing and that key workers sometimes actively showed their disappointment when the people they support relapsed. This reiterates how the expectations set are centred around services and the people working in them rather than the people needing support and their goals. The group talked about the importance of services not giving up on people or passing judgement if someone relapses or takes steps back on the journey to recovery. Kemi's experience illustrates why goals should be set by individuals and how setting these goals empowers people.

4.2 Relationships and community

This section focuses on relationships and how they can have an impact on the lives, wellbeing and outcomes for people experiencing multiple disadvantage. We refer to relationships with friends, partners, peers and family. We also refer to relationships with support services because for many people this relationship can be a key part of their journey and moving forward.

Pressure on existing relationships

The challenges of mental ill health, homelessness, substance use and contact with the criminal justice system can put pressure on pre-existing relationships.

> *"When you're skint, you're using and you're all in each other's pockets and you're buying and lending and selling the stuff to each other and just going round each others' houses and scrounging off each other and, it's just, you just kind of get f*cking, pardon my French, get sick of the sight of people and makes you resent each other, makes you resent the friendship because you know it's like … essentially just enabling an addiction that you've got."*

This extract highlights tensions that can arise in relationships with others facing similar challenges. Anton who is recovering from alcohol addiction explains how he avoided going to certain places to moderate his drinking and also that of other people:

> *"When I do go and have a drink in the street now, I choose my own little spot where I don't know no one […] I go a different route sometimes 'cause I know if I go that way, so and so's going to be there, so I'll go a different way so I don't bump into him. And even my keyworkers say, 'That's the best way to do it, [name]. Even though you're still drinking, try and avoid them 'cause you'll end up starting raising your tolerance again, it'll go up again, up to like 10, 12 cans a day, sort of thing.'"*

In many cases people spoke of how they had to leave some relationships behind to move on and support their own wellbeing. People lost relationships because of the challenges of their situation.

> *"Yeah, I don't, I don't have many friends… I moved around a lot … in my life and so, friends that I was, when I was at art college with are no longer in my life because I just destroyed the relationships, so they just don't want anything to do with me, so yeah."*

Relationships and well-being

The research found that when people have been abused by perpetrators or stuck in unhealthy relationships their self confidence is corroded (by perpetrators); and therefore, they are unable to make boundaries clear and be assertive in relationships. In other instances, people may have not had positive attachments to learn about healthy boundaries. It can mean people get involved in relationships that do not support their wellbeing. Clara describes how through a course about assertiveness in relationships she was able to have more control:

> *"Because I was out and someone asked me to go home or meet up with them and I had the courage to say no. I don't want to get mixed up with this kind of person. Whereas … before maybe, I probably wouldn't have had that … in place, if that makes sense. I could handle it…"*

Building confidence and self-worth in regard to relationships is especially important for people who have experienced domestic and/or sexual violence. Perpetrators often exploit people who are vulnerable, perhaps as a result of mental ill health or substance use. The nature of abuse combined with a lack of options can mean people find it difficult to leave perpetrators. In other situations, participants spoke of how they had to learn who they could trust:
"I think I'm too open, a counsellor said to me, 'Not everyone has your best interests at heart, [name], just remember that.'"

When people start to move towards recovery, the support they can receive from others who have a shared experience can be integral. This is reiterated in the FLLSL evidence base[xix] and explained by this participant:

> *"There's been one or two people that I used to use with who were like, they were but I think they may have seen me just getting clean and whatever and they thought, let's give that a bit of a go. So, yeah, there's been some people that we've kind of reformed or changed our dynamics of the relationships and … I've also had some people who, I've got a mate who was already in 12 Steps, so his, our relationship just got stronger if anything, because he's been in it for a while and whatnot."*

Participants spoke of reconnecting with people they had lost touch with. For example, one participant lost contact with his children during his addiction because he lost his job and was unable to pay child maintenance. He is now in recovery and able to have a relationship with them again and contacts them on a regular basis. For others a major change or transition in their life meant they were able to reconnect with friends and family. Donna who has recently moved into housing through Housing First and has a cancer diagnosis explains, *"With my health diagnosis I have now been in touch with friends and family who I haven't spoken to in years, and it has made a big impact on my life."*

Supporting a friend, partner or family member experiencing multiple disadvantage can be difficult and challenging; however, when people have supportive relationships this can be key to their recovery. David talks about his relationship with his sister during detox:

"She actually give [sic] me some encouragement and [tells me to] just keep up doing what I am doing. So I just had to keep doing what I was doing because she was an inspiration, do you know what I am saying? Because she was backing me, telling me to keep doing it."

Sean describes the support he received from his partner, which enabled him to get the professional help he needed:

"I think because my partner kind of took charge of that situation, he just said, 'We need to do something,' so he kind of took the lead on that. So, I guess my part in asking for that help wasn't, wasn't, wasn't too big. I think some of those decisions were taken for me because I was in no state to, I knew I had to do it but he kind of took the lead."

Figure 10: Piece of reflective writing from Sarah Hough (Research Officer, Groundswell)

"Relationships, we all need them and even more so when vulnerable or going through major life changes or transitions. For me, starting my recovery outside of rehab, I felt isolated and lonely. The circle of friends around me continued as normal visiting pubs and nightclubs and festivals. I was still invited but I knew I couldn't take the temptation and after a while they realised I was serious and the invites stopped. I felt weak for not being able to have fun like they could and I was envious and missed the lifestyle. I see it now as self-care and but at the time I resented having to make these changes by myself. I started to frequent a recovery centre called 'The Harbour' and soon built friendships and relationships with their excellent staff team. It gave me structure and the opportunity to meet people who were on the same page as me. The 'peer' support element was really helpful and supportive with a non-judgemental approach and the sharing of experiences and coping skills. There were also opportunities at The Harbour to try new things such as yoga, art and boxing. This has helped me to develop healthy hobbies which I have continued and to make new friendships and support networks. It was really important to me to have a safe space and The Harbour certainly provided an environment for me to heal and grow. Even now, years later, I know I can pop in for a cup of tea and chat with any of the staff or … the manager who I know is rooting for me and all the others who use the service."

Relationships with support workers

As seen earlier in chapter 3, relationships between people and those who are supporting them are integral to moving away from multiple disadvantage. Relationships change and meet different needs over time and some participants in this research spoke of how at times the relationship they had with a support worker was the most important one they had; however, others spoke of disconnection between them and the people who support them.

Participants suggested that boundaries between practitioners and the people they support are important, but there is still a need to develop a relationship and trust:

> "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 they are kind of mistrusting you, you know?"

Boundaries are there to protect both the person accessing support and the support worker, but participants felt that people working in services were overly cautious and appeared reluctant to build relationships: "And there is a currency not to engage socially [among professionals] because then this thing about 'oh, you mustn't be close to your clients'. Not a matter of being close, it's a matter of rapport." This participant felt that building rapport and getting to know one another was key to developing a trusting relationship. The importance of rapport building is also highlighted by Nina:

> "It just happens that sometimes you get a worker and you just … don't click. You don't have a good – you feel like you have to build up a working rapport with your workers. That helps. Because you … I am able to talk to them and there is trust there. If you don't have that then it's already broken. But I have been really unlucky with workers, I mean … they always seem to leave. I know this happens, but I think it has happened to me quite a bit."

Importantly, building rapport and getting to know someone beyond their 'issue' does not need to compromise professional boundaries. If people are finding it is difficult to work with a support worker, alternatives should be offered.

It is clear from this research that relationships play a key role in supporting people in their journey – this is especially true at a time of transition, for instance, moving to a new house or out of rehab. There are complexities at play for people to navigate. Participants spoke of needing to let go or leave behind relationships that do not support their wellbeing, but this can leave people at risk of isolation and loneliness or losing their support networks at a critical time. It is at this point where trusting and meaningful relationships with support services are particularly key. The following experience from a person supported by the FLLSL programme illustrates the value of supportive relationships during a period of transition. This example also illustrates how important it is for services to work with people around their interests, passions and choices rather than the challenges they experience.

Building and maintaining positive relationships is especially complex for those who have experienced trauma within a relationship. Despite it being an integral part of 'recovery', support for people to help manage their relationships was not common. Services often deter people from what they deem as 'negative' or 'unhealthy' relationships rather than focusing on building healthy and positive relationships. Spaces and opportunities for people to make new relationships, in a safe environment, are key.

Reflecting this, a key focus on support provided by FLLSL is around building relationships.[xx]

Case study

Power, trust and relationships

The sense of control and power people have over the support they receive has had a huge impact on their recovery and wellbeing. At times, the power dynamics that exist between services can hinder how trusted someone feels and their sense of empowerment. Ajoke, a support worker at FLLSL, illustrates how COVID has forced services to put their trust in people and how this can have a significant impact on their recovery.

"So [COVID has] also show[ed] … that …. you can trust people a lot more. I think often services don't really trust people … and I think that is really like giving people more responsibility and more trust…"

He further explains why trust is so is important:

"[It] is also like part of humanising people and giving people a feeling of strength and independence and autonomy over their health, their life and wellness, rather than something that is within the hand of someone else, which makes it really easy to abandon that offer, when it is controlled by someone else. When you have more control over your care and your health – like you might need a bit of support to manage that, but essentially, I think it is the way to encourage people to continue living well, when they have more autonomy over those things."

When people have control over their own care, they can become less dependent on services as Ajoke's colleague Paul, a peer link worker, describes:

"They feel like they are not so dependent on services, which is quite amazing. Where they said they get very dependent on you, they have become independent. Not … not leaps and bounds, but they are recognising, where they would say, 'Oh, I need to get in touch with…' and they would say, 'It's ok, I will get in touch with them.' Where before it would be 'oh, could you contact them for me'. So yeah, they are becoming independent and doing things that they need to do."

4.3. The power of shared experience

Strongly connected to listening and control is participation and co-production. What we mean by participation and co-production is how people are involved in decisions about their own care and how decisions are made in relation to service design and policy development. In this section we give examples of involvement as described by participants and the impact that this involvement can have.

To initiate a conversation about this we asked participants about the extent to which they agreed with the statement: "I have been listened to by services and they have implemented my suggestions." Notably the words 'co-production' and 'participation' were only mentioned once and instead participants referred to 'peer support', 'peer involvement', involving people with 'experience', or those who 'understood their situation'. As one participant put it, *"Been there and got the t-shirt."* In addition to this, participants described 'participation' activities, for example, peer groups, being involved in training and employing people with lived experience. Given this, it is important to consider the use of language and how 'co-production' is described. The following extract is written by Charlotte who is an FLLSL ambassador, member of the National Expert Citizens Group (NECG)[14] and has been supported by the FLLSL programme.

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[14] 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.

Case study

Charlotte M's experience
(extract taken from FLLSL Annual Review, 2020 – read the full piece here)

"I was referred to the programme in 2016, having just returned home from a treatment centre outside London. I have accessed numerous substance misuse services and treatment programmes over the last 18 years, and I can honestly say that Fulfilling Lives is a very unique and exceptional programme… I was asked to be part of the recruitment panel quite early on, which was initially a rather anxiety-provoking experience, but after encouragement from the team, I began to really enjoy it. I have always felt that I am an equal part of the panel, working alongside the project leads and other managers in our partner programmes, and that my opinion and insights are genuinely taken into account.

"I am now a NECG ambassador for the programme, which is a very dynamic and rewarding role. I am able to act as a voice for our beneficiaries in the regional and national meetings, meaning that our collective lived experience is used to influence the delivery of existing services and shape the design of those to come. We are currently working on designing a pilot project in line with both the Fulfilling Lives and NECG's system change priorities, true co-design and co-production.

"On a personal level, I can speak publicly in groups of over 60 people now, which I could never have done before, and I credit this to the constant encouragement and support that I receive from every member of the Fulfilling Lives LSL team. I have attended, and managed to speak up in System Change Action Network meetings and Shared Learning Forums, because I feel that my insights are valued, and more importantly will be acted upon.

"My roles within the programme have helped me in so many ways, I've gained in confidence, and have developed a repertoire of transferable skills. I very much feel part of the team, I'm really welcomed when I come into the office, and I was very honoured to be awarded the 'Michael Rosen Award for Best Volunteer' last year, a big surprise!"

Peer support

Within this research, participants spoke of how the involvement of people with 'lived experience' was key to helping them move forward:

"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."

This is also reflected in Charlotte's experience highlighted above; the people supported by FLLSL have access to workforce with lived and learned experience of multiple disadvantage.

Many participants described the quality of support they received within peer support groups in the area:

"There's just a lot of other support around anxiety, because anxiety was one of my biggest triggers, so there's a lot of support around that, there's a lot of, there's a lot of sharing, everybody's experience is different but everybody can learn from everybody, and a lot of this stuff is, I would say it's kind of peer focused, so there is obviously a facilitator at each group, but a lot of it comes from the attendees that attend, like myself."

Notably, where people with experience of multiple disadvantage were employed in roles supporting others, this made a significant impact on the relationship developed between the support practitioner and the person they were supporting. Having a group of people who are all at different 'stages' of a journey was also key to the success of such support groups.

"So, The Harbour, and it's good because it's very person specific. We had both the groups, so a lot of peer support, it's very open, it's really wonderful that you can be at any stage, you can be using, not using, whatever, any stage, and there's still loads of support around. It's really wonderful."

Participants felt that having people to talk to, and spaces to talk in, with people who understood and who were non-judgement was vital.

"

"Well, I think like, you know, I think what you guys do, and like you know, [referring to Groundswell] experience of mentoring myself and they know that when people come to see us, they tend to be quite surprised to, you know, there's a lot more understanding, there's a lot more friendliness, there's a lot more feeling of kind of openness. I'm sure you've experienced that yourself." (Research participant)

It is important for people to be able to share spaces and build relationships with other people who have experienced something similar: "*Because your average person hasn't experienced the same as someone who's been through addiction or homelessness or whatever, so it is nice to be able to relate to people.*" In such spaces people can share helpful suggestions and give advice to others. Such advice is often rooted in real life experience, which is often more helpful for people.

> "*I think you find out through people. Realistically I think it's from other people in my situation. It sounds crazy, being homeless I found more information talking to other individuals out there than in a book or on the computer, if you know what I mean.*"

Another important aspect of peer support was the opportunity to 'give back' and help others who are experiencing similar issues. "*I think it's good to help people, give something back to society, who helped me. I think it's a two-way thing.*" This raises an important point that co-production is a two-way experience. People who have experienced multiple disadvantage often want to help others in a similar situation. People need to feel needed and that their contribution has value.

Lived experience in shaping services

Participants described how through their 'lived experience' they could play an important part in shaping services and in turn help to improve outcomes for others. Through their experience of training professionals within the criminal justice system and mental health services, Josh tells us:

> "*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.*"

Mason echoes this and explains what he would like services to know:

> "*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. But certainly,*

> *peer mentoring and peer support is something that I think they could do a lot better with…"*

This suggests that co-production can not only help to improve services but also have a therapeutic role for those involved. Participants also strongly felt there should be more paid roles for people with 'lived experience'. This in part is because people feel more comfortable talking to someone who understands them:

> *"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."*

A theme around the practitioner workforce not being representative of the people they support was also identified in the system mapping for this project. Participants who had support from people who had a similar experience spoke of how it made a difference to their recovery. This is reflected in the experience of FLLSL beneficiaries who receive support from practitioners who have experienced similar challenges.

This points to a possible tension where existing practitioners may feel threatened by those with 'lived experience'. In this research it also became apparent that people shared ideas with services, but suggestions and ideas put forward were not often put in place. When asked the extent to which they agreed with the statement, "I have been listened to by services and they have implemented my suggestions", TJ explained:

> *"They have said I've got lots of good ideas… But they've not done anything about them."*

As illustrated in this example, where co-production falls short is the point of being able to implement and enact on suggestions from those who use services. While not all suggestions can be implemented, it is important that when people are asked for their input that there is an intention to implement what it is possible to do or explain why some suggestions might not be possible. As we found in the systems mapping there are often limited opportunities for a dialogue to develop between policy-makers and people with lived experience. For services to reflect the needs of people there needs to be significantly more conversation. FLLSL has been working on resources and facilitated workshops to support other organisations with co-production.

4.4 Informed approaches

Trauma, gender and culturally informed approaches overlap and interconnect. These approaches recognise the specific experiences people may have based on trauma they may have experienced, their gender and/or their culture. Services can use trauma, gender and culture-informed approaches to give more holistic and person-led care which is responsive to these needs. This next section details the prevalence of trauma, knowledge of trauma and gender-informed approaches and how this can impact the attitude of people working in the system and the environment services create. The work conducted by FLLSL is underpinned by the principles of trauma, gender and

cultural awareness. FLLSL embeds this in the programme through workforce development activities, system pilots, co-designing in a gender-informed way and developing informed approaches champion roles.

The prevalence of trauma

It became clear in the research that most participants had experienced trauma. Participants disclosed experiences of neglect, abuse, violence, poverty and severe mental ill health. For women, trauma was often a result of gender-based violence. Many of these experiences started during childhood. Gender and trauma-informed approaches are often the ones which are given more attention, but knowledge and understanding of a person's culture, ethnicity, religion, sexuality, age, and ability are also vital. These factors can be described as a person's identity. Notably not only women disclosed experiences of abuse, but also men.

It is very important for us not to retraumatise participants. Instead of asking explicitly about the trauma they had experienced, we focused questions on how services had or had not supported them and/or understood the issues they had experienced. Questions included: do you feel your services consider the experiences you have as a woman and do you think services recognise the difficulties you may have had in the past.

The following section explores these approaches and details what participants felt these approaches should entail; the main ones identified are knowledge, attitudes and environment. Some of the suggestions range from simple, tangible and practical to the more complex and intangible.

Knowledge of gender and trauma

One important factor identified by participants was around knowledge and the extent to which practitioners understood how their experiences affected them. Vanessa who was abused as a child details the connection between addiction and trauma.

> "It's called trauma-informed care, and what it suggests, that if you have someone that's really struggling with alcohol, I mean my friend who works with alcohol, she said that a high percentage of them have had neglect and abuse, that there are these core issues. And when I looked at bipolar and personality disorder, they say … 70% of them have experienced abuse as children."

When participants had been supported to understand the connections, this had often led to better mental health support and/or progress for them. Bethany describes how knowledge of trauma has improved over the years:

> "If I talked to someone, like I talk to a counsellor now for my … god, fantastic, it's made my eyes open about how I grew up, how it was, why things happened to me, why my mum was like this. You know what I mean? You find out things. But 20 years ago, who the hell talks to a counsellor? 'Ah, forget about it. You need a drink. Come on, let's go out. You'll be alright…'"

Michelle adds the importance of understanding trauma:

> "I mean because I got diagnosed with bipolar 20 years ago. And I was in [unclear] therapy. That has actually recognised and helped me to understand the trauma and it was recognised when I was homeless, definitely it was recognised when I was homeless. I wasn't on the waiting list for as long as other people had been on there. So, I know it was definitely. Yeah, useful then. Useful? Is that the right word?"

One participant used the taking part in research as an example of gender and trauma-informed approaches. A member of the research team asked if the participant would prefer to talk to a man or a woman – with the knowledge that many women in this research were likely to have experienced gender-based abuse. She explains:

> "You know, it's very, you know, sort of simple things, so for example, you said to me, you know, would you prefer a female to interview you, and it's been arranged with yourself. That question is not routinely asked. Now, in my case in particular, I have a history of sexual violence, so I really do need that. However, just as a female, it probably would be what most females would prefer."

As a result of understanding more about trauma, 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.'"

Knowledge about and understanding of people's context is clearly important, but participants spoke of how services did not always have the time to get to know people and their situation.

Understanding identity

Alongside gender and trauma, knowledge and understanding of a person's identity, for example their age, race, sexuality, gender and ethnicity, and how these intersect and impact experiences/access to services is also vital. This is because access can be harder because racism/ homophobia/ sexism and lack of specialist services.

Explaining how he feels his gender and race may have had an impact on the way he was perceived Tyler shares:

> "I am a big, black male. People sometimes feel … they find me frightening, because I use to be a body builder. So, I am a big person. But I don' t… aware sometimes how you come across to people.

Because I usually speak, when I speak I use hands. My hands are always going. And sometimes people can find that a bit frightening."

Lyda, who grew up in a country outside the UK where there is a different cultural understanding of mental health, explains why it was difficult for her to build trust with services in the UK.

> *"In my country … as a suicidal teenager. And they say are you doing this to get attention? So yeah, it's a bit scary still. I am still scared and I don't know who to trust because of my experiences. I know this country is different; I am getting more support; I am not treated like … I am doing like things for attention or something."*

> *"They don't explore, you know, any real depth. […] instead of saying, 'What's wrong with you?' they need to say, 'What happened to you?' And that's the, there's a shift of thinking, a massive shift of thinking."* (Research participant)

Sandy also describes how they found it difficult to ask for help as a result of cultural context:

> *"It's my culture that I come from; you didn't ask for help. If help was given to you, you kind of begrudgingly took it. I still struggle to ask for help. So if I ask for help it takes me a lot of … got to get deep to actually utter those words and say, 'Can you help me please?' I struggle with that, even today. I've been living in this country for 20 years. I think it's something I'll die struggling with, asking for help's very difficult."*

Not only is it important for services and professionals to consider a person's identity but also for professionals in services to consider how aspects of their own identity can impact on relationships and the support they provide.

> *"I have had issues where the people that have been in charge of us have been religious and they have pushed their religion on to me. Like, 'Oh, why don't you try praying?' I said God can't help me. If God wanted to help me, he would have done it by now."*

In this instance the religious beliefs of the case worker had a negative impact on their relationship with the person seeking support, who felt it hindered his progress.

Attitudes and knowledge

Knowledge and understanding of people's experiences shape the attitudes of services and the professionals within them. Tessa explained (see quote on the right) how she felt practitioners needed to have in-depth knowledge of

the different ways in which trauma can manifest and that this would lead to a shift in thinking within services.

Attitudes that do not consider a person's gender, trauma and context can have a direct impact on the person's outcomes. Sharing her experience of trying to get support for her substance use, Faith tells of how the approach taken by the service made her fearful she would lose her children:

> "I think in the past when I was working I tried to go to a drugs and alcohol advice place and I just wanted them to tell me how … I could stop drinking, that's all I wanted to know, and they would say things like, 'Don't go to the supermarket, avoid…,' and I found it hard when they would say, you're a mother and you have a son at home, you know, and just putting the fear of God into me of going there because they would look at taking my child away… So, I think there could have been different ways of approaching it because I just didn't go back."

Women in this research who disclosed that they were survivors of abuse explained how they could be labelled as "hysterical", "liars" or "manipulators" and the impact this had on their trust in services and the support they may receive. Some women have been labelled with a diagnosis of a personality disorder which is deemed untreatable and therefore no support is provided.

> "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. And I know very much my children and my family now don't trust the police or social workers."

Jade adds how she was not taken seriously when she was being abused by her partner:

> "In the past the biggest mistake I made with professionals was screaming, 'Help, help, that man over there is hurting me,' you know, a bit too like a stereotypical crazy, mad woman. And if he's very calm and there isn't obviously a punch in the wall or a broken window, and you look OK, and he's holding the baby and the baby's quite calm and happy in his arms and he's talking smiley and sweetly and he offers them a cup of tea…"

This example illustrates how services may lack understanding gender informed approaches and of how trauma might affect how someone communicates and behaves. These barriers around knowledge and attitudes are also evident in the systems map. The map explains:

> "The stigma experienced by people experiencing multiple disadvantage, and a lack of understanding around multiple disadvantage, can compound a 'them and us' perception, which can be seen at different levels across the system."

It is evident that there is a specific need to recognise the experiences of people may have been based on gender. This is reflected in the system change priorities identified by FLLSL.[xxi]

Environment

Service professionals' understanding of people's experiences and their attitudes impact on the environment in which people are accessing support, which can impact on their recovery. Factors that can impact recovery can include the people involved, the location of support and how comfortable it is. Lucy who had experienced severe mental ill health and has disabilities shares some of the things she felt were needed to create an informed environment:

> "'Do you have any needs getting to the appointment today? Is it OK that there's stairs?' Or, 'Oh, to let you know there aren't going to be any…' you know, like in a professional capacity. Whenever I've got involved with anything, like, that's not charity or government, you know, job interviews as such, you know, you're offered a cup of tea, you're made to feel welcome, you're treated with so much more humanity."

It is important that support workers consider the impact a person's environment can have on them. Clare, who had been violently attacked and had her spleen removed as a result, shares how she was put back into the same building where the attack happened:

> *"And it's like you are not, and you're not even talking about something difficult, you know… I'm not expecting there to be like cappuccino and croissants, you know, it's like, but a glass of water, you know?"* (Research participant)

> "When I got attacked, right, I was in a coma for two-and-a-half week., I lost my spleen 'cause my ex-partner, obviously, he punched me, right, and I had to have a major operation. When I came out of my coma, my daughter was there, and my sister, and [outreach worker] was there, the outreach worker, but they put me back into the same hostel. I says, 'Why's you doing that?' How the hell do you think I felt? I was traumatised."

It is important that people have spaces where they can feel safe to talk. Milena, who was living in a COVID-19 hotel at the time, explains the importance of having a space where she could talk privately about her mental health and immigration issues:

> "And there are people coming to the hotel, but I said, 'I don't want to talk in public space about all these things because it's kind for personal,' and they didn't give me an option. Like to having a private conversation with these people. They do it in like a café or a sort of … people who stay in the hotel just standing around."

Joyce adds her experience of a personal independence payment (PIP) assessment and how there was no consideration of her trauma or gender and that two men carried out her assessment.

> *"You don't necessarily have to have trauma, you understand? So, one, I had a health assessment by the DWP [Department of Work and Pensions] that took place in a room with closed door by two men touching me. Now, it said on my notes everything, so that should never have happened. But then I think that, and I ran screaming from the room, but when I thought about it afterwards and I broke that down, I thought, actually, that shouldn't have happened to any woman."*

Summary

Listening to people, giving them choice, and empowering them to make their own decisions can have a transformative impact. Involving people with lived experience in the design and delivery of services is critical in ensuring services reflect the needs of people. Furthermore, co-production can also have therapeutic value. We also explored how approaches that take into consideration a person's trauma and/or aspects of their identity (for example, their culture, gender or race) can have an impact on the extent to which their challenges are understood by services and by the person themselves. Gender and trauma-informed approaches, like a person-centred approach, address the need to look at the whole person and their context, rather than focusing only on the issues they are presenting with. This then has an impact on the support a person receives and the environment in which they receive it, ultimately impacting on their wellbeing and recovery. Connected to co-production, informed approaches and outcomes for people experiencing multiple disadvantage is the importance of relationships. The following extract from an interview with Philip is a thoughtful account of how an informed service and support look and feel.

Case study

Philip – relationships and person-led approaches

"When you speak of services you're speaking of … a thing, not a person, you know. The people within the thing, like you know, a therapeutic relationship. You form a therapeutic relationship with somebody and I feel like that's understood by those people that you can create that therapeutic relationship with. Not all people have that ability or just I didn't have that connection with them. But 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."

5

Conclusion

In this research, we have created a picture of what is happening, how it is happening, and why the system is or is not working for people experiencing multiple disadvantage.

We have explored how the system can impact people's access to services. We have illustrated how transitions are key points in a person's journey. More broadly, we have detailed how the attitudes and the entrenched ways the system works can be detrimental to wellbeing and recovery. Much of what we have found through conducting this research is, sadly, of no surprise to the partners and experts by experience involved in this research. We heard repeated narratives of people needing to 'hit rock bottom', 'tick a box', 'passed from pillar to post', 'jump through hoops', 'give up hope' and 'look like someone who needed help'.

The findings highlight the non-linear 'journeys' that people make towards recovery, which may contain successes, setbacks, and plateaus along the way. The complexity of people's lives and how multiple disadvantages are bound together are still, at times, misunderstood. In particular, the evidence in this report underlines the need for support organisations to operate in complementary ways and to 'see the bigger picture'. Linked to this, it is clear that recovery journeys vary widely, and people often need ongoing, long-term support especially during periods of transition. Often, the short-term nature of projects and schemes is welcome, but largely insufficient. The participants in this study welcomed services that were respectful and actively acknowledged their difficulties, traumas, and unique situations. Conversely, it is clear how much frustration, anger and apathy is experienced when services are not informed in this way. And, there is a very mixed picture.

There are pockets of good practice where people felt listened to, spaces where people could drop in and situations where meaningful relationships were developed. Participants shared experiences of how attitudes towards addiction and mental health had changed in recent years. Services with models of peer support showed how valuable 'lived experience' can be and how services and the people working at them are increasingly understanding the impact that trauma can have on people experiencing multiple disadvantage. There is, therefore, a requirement for more services to radically change their practices, for services to share their good practice, and

for the people who use services to have their experiences and ideas taken into account. To drive this change for the better, we need to understand what has been effective and leads to positive longer term outcomes. The experiences of those experiencing multiple disadvantage are a critical part of this, and this report provides key insights into this.

Recommendations and learning points

Based on the findings of this research we conclude this project with a series of learning points for commissioners and services. The findings highlight how the system is not working for people who face multiple disadvantage. But with steps taken to change how the system works with people experiencing these issues, and the will and resource to make these changes from commissioners, there is the opportunity to redesign a system that works for all. As part of this process of change, Fulfilling Lives will continue to respond to the needs of the people they support and to deliver key systems change activities.

For commissioners

Commissioners and the commissioning process shape how support services and delivered and how they can respond to the needs of people who access support. To truly meet the needs of people who face multiple disadvantage commissioners should drive forward responses that are coproduced and built on the principles of flexibility, collaboration and being person-led.

1. **Develop a joint strategic needs assessment on multiple disadvantage.** Local boroughs should develop a joint strategic needs assessment (JSNA) on multiple disadvantage, and apply the JSNA to ensure it informs all strategic commitments across the borough.
2. **Participation in commissioning.** Commissioners should seek to embed coproduction across commissioning activities so that people who are experiencing multiple disadvantage can shape how support systems meet the needs of people experiencing these issues. This should include the design of services and commissioning tenders, assessing proposals and on interview panels, and the ongoing delivery and monitoring of services.
3. **Building structures so services work across disciplinary boundaries**. When support services are commissioned to address issues like mental ill-health or substance use there is a need to build structures to ensure that these services collaborate and work towards coexisting issues that the people they support might face. Multidisciplinary meetings and collaboration should be outputs built into tender agreements.
4. **Ensure support in place for those with a dual diagnosis.** 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 coexisting issues.

5. **Flexible support responding to individual journeys.** While services that support people in a 'crisis' play a critical role, there is a need for support that adapts to the needs of individuals and their relationships before they reach crisis point. Commissioning services that have no 'threshold' for access, have the freedom to connect and build relationships in a preventative way, and can respond to the 'ups and downs' of recovery is needed to meet this. Commissioners should ensure that adequate services are available to support people to prevent further crises.

6. **Support for people in transition.** Commissioners should also 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.

For support services and organisations providing support

This report indicates what people with experience of multiple disadvantage regard as positive and negative aspects of the services they receive support from. The evidence points to good practice in the way that support services work with people experiencing multiple disadvantage. These are:

1. **Person-led and psychologically-informed approaches.** It is well evidenced that models of support that are flexible, compassionate, consistent and centred around individual need can have a significant impact on people experiencing multiple disadvantage. Support services should move toward delivering support in a way that is person-led and informed by gender, culture and trauma.

2. **Gender-informed leads.** Support services like day centres working with people experiencing multiple disadvantage have to cater to the needs of many individuals from different backgrounds and circumstances. In this context having a designated staff member to promote and embed gender informed approaches within services can help to make sure services meet the needs of women.

3. **Strengths-based support.** Services and the people who work in them should look beyond the labels of multiple disadvantage and understand that it is not a 'choice'. Services should support people to see the qualities they have, set their own goals and respect they decisions people make.

4. **Training and support for staff.** Staff and volunteers working in support services need to be trained to work in a psychologically-informed way and be given psychological support so that they can safely provide support to the people they work with. They should be equipped to understand how trauma impacts on the individuals they work with and respond appropriately.

5. **Space to build trust and relationships.** Trusting relationships between people experiencing multiple disadvantage and the people who provide support are key to recovery. To achieve this, people in

support roles need to have the time and capacity to build these relationships away from key work sessions.

6. **Diversifying the workforce and support offer.** Connecting with people who have experience of multiple disadvantage to work in services and provide support can help to make the organisations and support offered more effective. Creating 'peer roles' as well as ring-fenced roles across the functions of the organisation, e.g. administration, finance and communications roles, should be adopted by support providers.

7. **Information sharing and recording.** Organisations providing support should focus on recording only the most needed information and manage it transparently with the people they support. Effective information recording can help to avoid repeated and unnecessary questions which can retraumatise people.

Response on learning points from Fulfilling Lives Lambeth, Southwark and Lewisham (FLLSL)

The FLLSL programme seeks to address the challenges and barriers faced by people experiencing multiple disadvantage. This is done through key systems change activities as well through the provision of a person-led, wrap-around outreach service for people experiencing multiple disadvantage. Key activities taking place as part of the programme to address the barriers and challenges outlined in this report include:

- **Co-production.** Co-production is at the heart of FLLSL. The programme is delivered by a blended workforce of lived and learnt experience, and works closely with experts by experience, Champions and Ambassadors, people we support, and people in the community.
- **Enabling access to services and supporting people through transitions.** FLLSL works to enable people to navigate and access the system - notably in times of transition. The support provided is person-led and founded on trust and relationship building.
- **Peer support.** FLLSL service is delivered by practitioners many of whom have lived experience of multiple disadvantage.
- **Developing and supporting gender, trauma and culturally informed approaches.** FLLSL are developing tools and resources to support services across boroughs to embed informed approaches, including the development of an Informed Approaches Champion role.
- **Co-designing gender and trauma informed pilots.** FLLSL are codesigning two trauma and gender-informed systems change pilots with the aim of improving women's access to services. The first is working with local drug services to improve women's access to treatment, the second is looking specifically at support for women involved in street-based sex work.
- **Providing spaces for joint working and shared learning.** FLLSL are committed to creating spaces and facilitating shared learning across the system. FLLSL have established a shared learning forum to support shared learning and communication between local services.

- **Building an evidence base.** FLLSL continue to deliver ongoing research and learning in relation to people's experiences of multiple disadvantage, access to services, and how the system operates.

Appendix

Appendix 1: Training sessions and participatory workshops with experts by experience

Session 1: About the research and an introduction to research methods

Session 2: Feeding into the research tool

Session 3: Understanding consent, anonymity and challenging our unconscious bias

Session 4: Active listening and interview practice

Session 5: Managing rejection, building confidence and interview role play

Session 6: Systems mapping workshop

Session 7: Reflecting on the year, Christmas games and role play

Session 8: Developing an online survey

Session 9: Feedback on systems map and case studies

Session 10: Feeding into case studies

Session 11: Analysis of data

Session 12: Analysis of data

Session 13: Reflective writing for the report

Session 14: Developing a podcast

Session 15: Feedback on the report

Appendix 2: Example of a session with experts by experience on unconscious bias

Free your unconscious bias

- Positive bias towards Scottish people
- Positive bias towards South American Indians
- Police
- Dishonest politicians
- People who think they are right all the time
- White people who wear deadlocks
- People who are too religious and try and convert me
- People who do not let old people have their seat on the bus
- Social justice warriors
- Leftist ideologies
- Rude teenagers
- People who shop in shops that are different to the ones I go to
- Drug addicts and criminals
- People who are more religious than me
- Positive bias towards Leeds fans

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