Women's Health Strategy

Evidence from Fulfilling Lives Lambeth, Southwark Lewisham

June 2021

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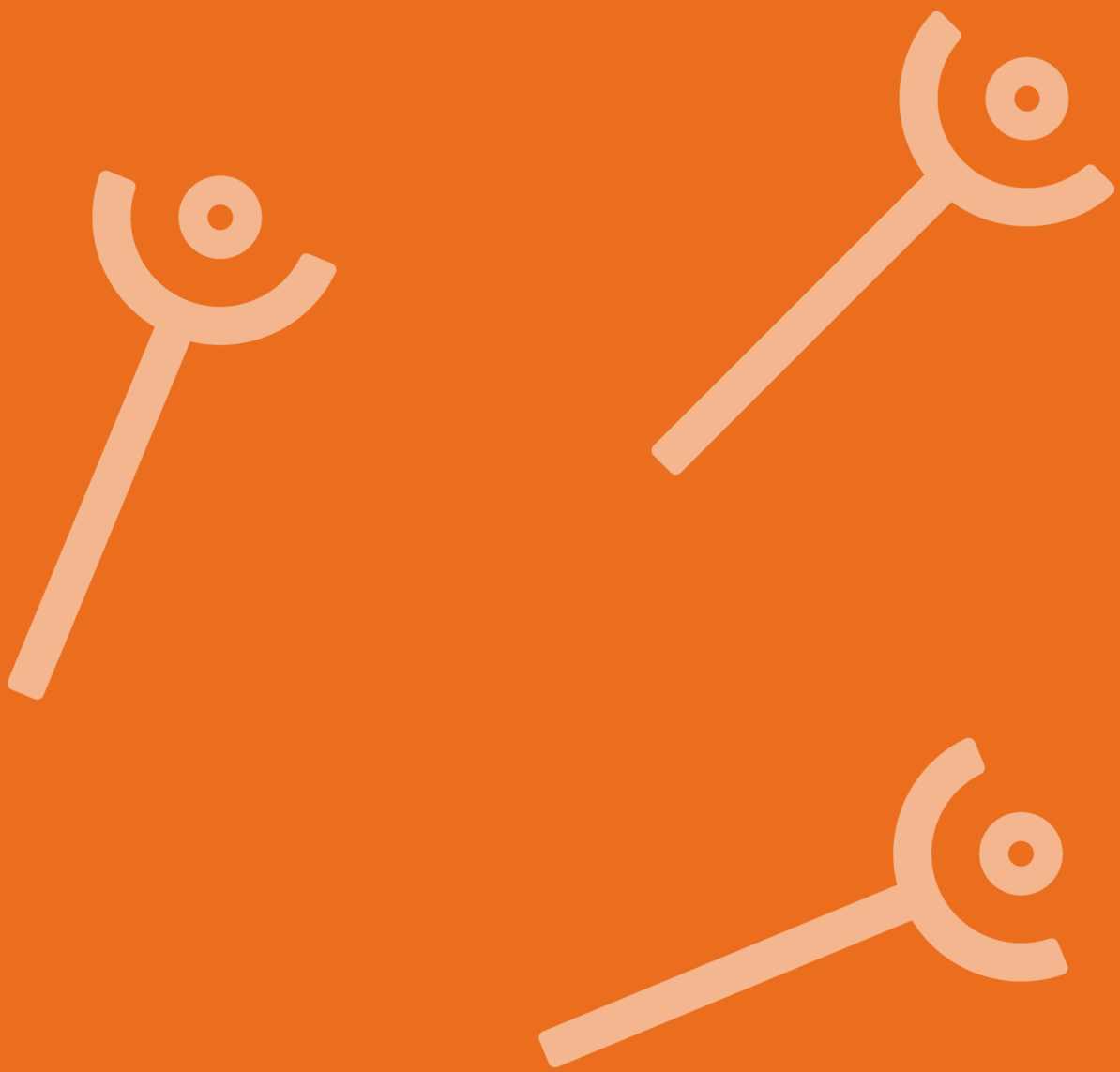

Fulfilling Lives Lambeth, Southwark and Lewisham Fulfilling Lives Lambeth, Southwark and Lewisham is funded by The National Lottery Community Fund and is part of the National Fulfilling Lives Programme.

This is a £112 million investment over 8 years supporting people who are experiencing multiple disadvantage; the people we work with have a combination and interconnected needs of mental ill-health, are homeless/or at risk of homelessness, substance use and/or contact with the criminal justice system. We acknowledge that the system doesn't work for everyone – particularly people who experience greater levels of disadvantage.

Certitude is the lead agency of the programme, delivering the programme in partnership with Thames Reach and strategic partners; South London and Maudsley NHS Trust and the three boroughs of Lambeth, Southwark and Lewisham. Our three core aims are:

• 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. To find out more please go to our website: https://fulfillingliveslsl.london/

1 About this consultation response

This document presents the evidence Fulfilling Lives LSL submitted for the Department of Health and Social Care's Women's Health Strategy consultation in June 2021. The consultation sought insights on the following key thematic areas:

- Women's Voices
- Women's health across the life course
- information and education on women's health
- Impacts of COVID-19 on women's health

Our submission present evidence and insights from the programme in line with these key themes. We also present 'Calls to action' for consideration from the Department of Health and Social Care.

2 Introduction

57% of the people we work with are women, who are required to access health and social care services for physical and mental health needs, drug and alcohol support, homelessness, social services as well as other parts of the system such as criminal justice, and domestic abuse; in our experience, these support needs are interrelated and cannot be easily separated. One of our main strategic priorities is improving women's access to services; this is based on the evidence we have that women's experience of the health and social care system is different to the male experience and women face specific barriers to accessing the care and support they need.

"Gender matters in the lives of women and girls at risk of extreme adversity. Gendered social norms and expectations shape risk across the life course of women and this is evidenced in women's different experiences that are associated with multiple disadvantage (e.g. homelessness, mental ill-health, reoffending and addiction)." McCarthy et al., 2020

This document outlines the evidence we have that is relevant to the core themes outlined in the Department of Health and Social Care's Call for Evidence. The evidence presented in this response is from women with lived experience of multiple disadvantage, our Research and Evaluation partnership outputs including a literature review and peer research, and the experience of Fulfilling Lives LSL team members.

3 Calls to action

Based on the evidence outlined below, we ask the Department of Health and Social Care to consider the following when developing the Women's Health Strategy:

3.1 Informed approaches

Steps must be taken to ensure that women experiencing multiple disadvantage have access to trauma, gender and culturally informed support. Services must recognise the trauma that women have experienced, respond to the impact trauma can have and that interactions with the system can re-traumatise. Services must understand the gendered experiences of these women and respond accordingly and consider individual's specific experiences depending on their cultural context. Services must develop and embed informed approaches and practice.

3.2 Co-production and peer support

Co-production must be embedded to ensure that the voice of those with lived experience is central in the development of policy, strategy and legislation change. We are determined to create a level playing field so that all opinions and experiences are respected to shape, design, evaluate and govern services and policy. Peer support should be offered as much as possible, as there is evidence that this helps women to feel safe and listened to when accessing health and social care services.

3.3 Violence Against Women and Girls (VAWG)

All health and social care services and practitioners should have an understanding of VAWG, including recognising the signs, knowing how to ask and where or how to refer.

3.4 More support

Support should be available for women when they need it, in particular, mental health support and drug and alcohol treatment. Services should offer flexible access in terms of opening hours and location.

4 Core theme: Women's Voices

4.1 Evidence on women's voices not being listened to within the health and care system

Women have told us that there are times when they do not feel listened to by health and social care services, in particular, when disclosing experiences of trauma because of male violence. Women can be labelled as 'hysterical', 'liars' or 'manipulators', and some women are labelled with a diagnosis of personality disorder which is deemed as untreatable and therefore no support can be 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. So, you know, I think it's, you know, and then this is, in the cycle of people when they get into things and, you know, and 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." (Woman with lived experience of multiple disadvantage)

This is reflected in wider research; in Sharpen's (2018) study, women felt that some services were quick to label them as not engaging when, actually, the service failed to understand their needs or appropriately engage with them. This left the women in the study feeling 'thrown aside' and invisible.

Women experiencing multiple disadvantage may need additional support to accessing services or have specific communication needs that are not always accommodated for and can leave them feeling misunderstood and not listened to.

"Talking to people is hard... People don't understand me, most of these people working in these places don't have communication skills, they just do their job and go home - I need extra support… they make me look like a monster… I'm claustrophobic so I don't like waiting in some box room, I get scared but then people act like they are in danger because of me, It's why I'm going to court… I need people around who know me… People are scared of me but they don't realise I am scared of them." (Woman supported by Fulfilling Lives LSL)

Sometimes, for women to feel able to be honest, it is important to offer support from female staff or have women-only access points. One woman FLLSL have worked with said:

"When I got to [the drug service] they didn't ask me if I wanted male or female worker, the male worker was asking me personal questions and it was harder to be honest, I felt like I had to lie rather than be honest because I didn't feel comfortable." (Woman with lived experience of multiple disadvantage)

4.2 Taboos and stigmas in healthcare related to gender

4.2.1 Sex Work

45% of the women we work with are involved in sex work, predominantly street-based. This group experience a lot of stigma and judgement from healthcare professionals. Often, healthcare staff have not had the appropriate training and are not able to respond to women involved in sex work's health needs in particular sexual health. Often, women do not feel comfortable disclosing their involvement in sex work due to fear of

judgement and shame, meaning they are not accessing the healthcare they need.

Generally, for all women, our experience is that sexual health is not a priority for women; whilst they do care about their sexual health, there are competing priorities including making money and purchasing drugs.

"I don't think sexual health is a massive priority to the women we support at the best of times – what I would say is they do care about their sexual health but their lives revolve around getting money and drugs so unless sexual health testing is really in their face it is hard – when I was doing it I would try and do it in the van, a client has done it in McDonalds, I had all those kits, so every time I was with a client I would do a sexual health check" (Fulfilling Lives LSL team member)

4.2.2 Blood borne viruses

Since October 2020 21% of women we have worked with have at some point did not access their GP, but needed to, and 27% had not had a blood borne virus (BBV) check in the last year, when they are at high risk of BBV transmission. Our experience is that there is a lot of stigma about HIV/AIDs. "We've got quite a few clients who are HIV positive, they don't necessarily deny it but they won't talk about it, they will only bring it up when they feel really bad or need to go to hospital… These little scenarios cause a battle in someone's head, why would she even talk about. No clients speak about it openly, throughout all my years working in support services." (Fulfilling Lives LSL team member)

"There's still a lot of stigma around HIV definitely, I know that some of people we support people HIV positive have had their status outed by other service users and been bullied – a lot of professionals are still really uncomfortable talking to people about their HIV status – if someone discloses they don't necessarily feel confident to talk about it – [which is] based in recognition of stigma, they know it's a difficult subject that could be handled badly" (Fulfilling Lives LSL team member)

4.3 Barriers and Solutions

Fulfilling Lives LSL believe in the value of co-production and peer support in overcoming the barriers described above. Peer support can benefit both the people being supported, and the peer supporter.

"We need more staff more understanding people – we need people who have had experience of it – not just I'm qualified I'm an experienced person. People who can show others that they've come through it – they will be more willing to stick with the programme if they can see someone else has been through it – give them positive thinking and encouragement they can do it – you don't want to sit there and feel judged by someone

who doesn't understand you" (Woman with lived experience of multiple disadvantage)

"I started working with women that I was - were homeless. That I had known from the streets that I had sat in crack houses with. So suddenly these girls were looking up to me. It was a fantastic...er...time for me." (Woman with lived experience of multiple disadvantage)

Co-production means giving equal value to the voices of both decision makers and the people using services, so that all opinions are heard and respected equally. In its most simple terms, co-production means working together to find a solution, change or improve something. By listening to the voices of women with lived experience throughout the design and commissioning of services, they will be better able to accommodate for women's specific needs.

5 Core theme: Women's health across the life course

There are specific health needs and experiences of health and social care services that are related to the experience of multiple disadvantage, including trauma, dual diagnosis and maternal mental health. We present evidence that services do not always meet women's specific needs, and support for new approaches.

5.1 Trauma and Violence Against Women and Girls (VAWG)

Women experiencing multiple disadvantage have frequently also experienced abuse and trauma during childhood and throughout their adult lives; 35% of the women we are working with disclosed experiencing physical abuse during childhood and 24% reported experiencing violence in a relationship.

"Because I have had…a lifetime of abuse, so I had it from my uncle, my dad and my brother. And then [unclear] the man I married, I was [unclear] so all I have done really, and having bad relationships is more or less sexual abuse all my life." There is a well-documented link between substance use, domestic and sexual violence, and mental ill-health; this is described in more detail in the literature review by McCarthy et al. (2020). Despite the evidence, this link is rarely reflected in the support available to women.

"Women should have more priority over men -we need it more than men, we need it quicker than men – we are more vulnerable" {on access to drug services} (Woman with lived experience of multiple disadvantage) Many affected by violence often resulted in using substances to help them with unmet mental health needs. One woman describes how she started drinking while she was waiting for support and then because of her substance use, she was no longer able to get the mental health care she needed.

"It was after I went to a woman's refuge and I started getting flashbacks, that I actually ended up seeing a psychiatrist. And the first psychiatrist…that was the awful thing, it was my first experience of psychiatry or going in a hospital or anything like that, and I saw a counsellor first and she said, 'I think you need to see a therapist, you're quite distressed', you know, and looking back I had symptoms of post-traumatic stress disorder. And this psychiatrist did, she just did an assessment for an hour and I never heard from her. And then about eight months later they assessed me and by then I was drinking. And once you're drinking, they won't give you psychotherapy." (Woman with lived experience of multiple disadvantage)

Many women who have experienced trauma and have interconnected mental health and substance use support needs have to wait a long time for specialist support. 52% of the women we have worked with since October 2020 need mental health therapy but have not accessed it.

"At the moment I am not getting any help with past trauma, bereavement, rape. I am not getting any – I think this is childhood issues. I think this is why finally I have been referred to this long-term counselling. But…it's not only to be long-term…like I said I have been waiting a year. And when I called up recently, they were like listen you are on the list but I couldn't tell you how long it's going to be. I said 6 months [unclear] I said a year? She was like hmmm, could be even longer than that. I said I have been on it a year. She said I know but due to the pandemic, but the therapy is long in itself. So, spaces are limited. That's just how it is. So, I am on the list but I don't know how long. Because I do feel like my trauma…childhood issues, rape, bereavement – I think all these things add to why I...I am in and out of recovery. In terms of my substance misuse." (Woman with lived experience of multiple disadvantage)

We have also found that where women were given specialist support, they could move on with their lives:

"I mean I suffered domestic violence, it was a very bad long path, a long, long journey, it was so, it was so, quite hell and back, but I've made it, yeah, I mean I fell, I fell and I cried, but I actually picked myself, I picked myself up in a way which no one really would have been able to do, the way I picked myself up, like from all the help and support I got as well." (Woman with lived experience of multiple disadvantage)

Services are often not able to offer flexibility in terms of when and how to access a service, which is crucial to enable services to engage with this group of women. It can also take time to build trusting relationships with staff which is essential in enabling women to access support and is key in a trauma- and gender-informed approach. Previous negative experiences of services mean that women are often suspicious of services and experience of trauma can impact on the times it takes to form trusted relationships.

Women-only spaces are especially important when a woman might be experiencing domestic abuse:

"How you meant to talk to someone if your partner is just there, you can't open up if they are there, they'll be shoving you and looking at you telling you not to say certain things" (Woman with lived experience of multiple disadvantage)

Our findings are that the lack of a gender-informed approach is a key barrier for women in accessing drug and alcohol services. Drug services can often be male dominated environments that can feel unsafe.

5.2 Dual diagnosis

Related to the experience of VAWG, is co-existing mental health and substance use support needs, 'dual diagnosis'. Our findings show that women's experience of substance use and mental ill-health was often a result of domestic and/or sexual violence whereas men had a different journey. Women often spoke of struggling to get these interconnected issues between abuse, substance use and mental ill-health addressed. If a person is experiencing both support needs, they are ineligible for mental health services and substance use services, meaning they do not get the support they need.

"And once you're drinking, they won't give you psychotherapy, they won't, they said that you, you know, can't have it. So, I was just assessed there, and they never really gave me a big diagnosis at that stage." (Woman with lived experience of multiple disadvantage)

"Because I remember saying to the community mental health team who didn't want me to have psychotherapy because of the drinking, I said I'd like to have a group…around trauma and one-to-one psychotherapy, and he said, 'You can't have both'." (Woman with lived experience of multiple disadvantage)

"I was supporting one of our female beneficiaries when her mental health deteriorated to the point where she wanted to take her own life. We spoke with her worker from the mental health team however this worker was adamant that it was the drugs and to present at A&E. The worker showed no empathy or understanding. This female beneficiary hadn't used drugs for a week as she was trying to get herself back on track. By our beneficiary not using drugs she wasn't able to cope with the trauma she has been exposed to throughout her life, she saw no hope in her future." (Fulfilling Lives LSL team member)

Our research into dual diagnosis shows gender differences between men and women's access to services.

	Substance misuse worker		**Detox**		**Rehab**		**Received mental health interventions[10]**	
Gender	Male	Female	Male	Female	Male	Female	Male	Female
Number	16	17	4	3	2	5	4	2
Percentage	84%	68%	21%	12%	11%	20%	21%	8%

Only 8% of women received a mental health intervention compared to 21% of men; and a lower proportion of women (68%) had a substance use worker than men (84%). There is however a higher proportion of women who access rehab (20% of women compared to 11% of men) although access to detox is lower (12% of women compared to 21% of men). It is unknown the reasons as to why this is; we are exploring this area further.

5.3 Cultural barriers

A woman's race/ethnicity, immigration status, sexuality, socio-economic position and experiences living with disability all impact experiences of multiple disadvantage (Ava and Agenda, 2019). One woman we spoke to describe the expectations around accessing services in her community as a barrier to support.8

"In the black Caribbean community its literally that we are just not accessing services when you're supposed to – we are being looked down on by family and friends – in my experience some of my friends told me 'why am I going into services?... why am I going to rehab?' they kept bringing it up. They kept me falling back into my unhappy patterns. It's literally being embarrassed – everyone is judging you, they think they know what you're going through, but at the end of they day they're thinking of themselves. I wanted to back out before I went to rehab I got so much backlash from my family and friends, it was so hard. It was hard and I found myself isolating myself from people – it made it more difficult for me because I can't be on my own all the time but I don't want them to be bringing up these feelings." (Woman with lived experience of multiple disadvantage)

5.4 Maternal health

78% of the women we work with have had children removed; this amount to 82 children placed in the care system. This is a deeply traumatic experience for women; one woman describes the impact of this on her mental health:

"I self-harmed so badly my whole arm was red, I lost the plot, my stepdad sectioned me, I got out of there within less than 12 hours though. What happened was the two ambulance people, they let me keep sleeping tablets enough that I had to overdose, they confiscated them in the hospital. They just let me go, they sectioned me for 28 days, but I was out after 12 hours. After that I was just out sleeping rough" (Woman with lived experience of multiple disadvantage)

We advocate the need for better support for pregnant women and mothers with a mental health issues. One suggestion from a woman we work with was to have support to attend mother and baby groups.

"This might help prevent the removal of children from their mums who are ill but still love them" (Woman supported by Fulfilling Lives LSL)

Women have also described the societal attitudes towards women and the perception that they should be 'homemakers' and care givers. Therefore, people within services and the general public can be less tolerant of women who use substances and perceive them as 'irresponsible' as they are not fulfilling their 'caregiving' role: "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. That's the only time…and yet that can happen to a man as well. So, I think there could have been different ways of approaching it because I just didn't go back." (Woman with lived experience of multiple disadvantage)

5.5 What works?

We advocate the importance of informed approaches to designing and delivering health and social care services. Services must recognise the trauma that women have experienced, respond to the impact trauma can have and that interactions with the system can re-traumatise. Services must understand the gendered experiences of these women and respond accordingly and consider individual's specific experiences depending on their cultural context.

It is essential that health and social care services offer flexibility around access points, locations, opening hours and appointment times. This is to accommodate the unpredictable lifestyles of many women experiencing multiple disadvantage, and those with children.

When someone has multiple support needs, they are required to access multiple services; navigating the system can be complicated and support should be made available to navigate the system.

6 Core theme: information and education on women's health

21% of the women we support have literacy problems, making written information about support available very difficult to access. A lot of information is available online; many women experiencing multiple disadvantage do not have access to the internet, or may not have the skills to use technology even if devices are available. Other research has found that women experience barriers to identifying the services that might be able to assist them including: not knowing the right questions to ask to get the answers they need; being over-reliant on the knowledge of the person they ask; not knowing whether they meet the referral criteria; and not knowing how good the service is or whether it still exists (Holly, 2017).

6.1 Drug and alcohol support

Some women described the challenges they had accessing information about the support available particularly around drug and alcohol support. Information is passed on by word of mouth and having awareness in communities is an effective way of circulating information.

"I had problems starting off – there wasn't much advertised… I found out because my doctor googled it online. A lot of people don't have access or knowledge about technology – people need access to technology to see so much of what is out there… More advertising [is needed]… – it took me a couple of years to access [support] because I wouldn't have known that there was help or even free help – I always thought I would have to pay for treatment." (Women with lived experience of multiple disadvantage)

7 Core theme: Impacts of COVID-19 on women's health

Our research into the impact of COVID-1913 found that changes to access to drug and alcohol treatment enabled women to get Opiate Substitution Therapy who were previously known as 'hard to reach'. This was largely due to the use of telephone appointments.

"There are less problems, I get to speak to the person I need to talk to quicker, before I would have to keep calling, waiting until I heard back from them". (Woman with lived experience)

These women reported telephone assessments to be more accessible than the previous queuing system. Team members believe that the motivation for some people to go on OST is partly due to the change in situation prompting some people to want to change their lifestyle and some faced difficulty in how they would normally earn their money during the quarantine.

One of the most negative changes in London was the loss of detox options, due to the detox hospital being used for overflow of hospital patients.

"Detox fell through due to COVID-19– the option is not open, and I was so close to going detox and then this happen it happen so quickly. I was getting ready to go detox then at the last minute everything changed. But I can turn around and say that it has enabled me to look t my health and I have been able to cut back on alcohol. I have turned it in to an opportunity to try to not drink anymore. I will keep on going until the services are back open, I may stop drinking completely and may not need to go back to detox." (Woman with lived experience of multiple disadvantage)

The impact of COVID-19 and the lockdowns on domestic abuse has been wellreported in the media. In our experience, women at risk in their own homes suffering as a victim of domestic violence have become more hidden. The traditional safety nets had been removed with a greater risk of the level of coercion and control being experienced. For example, team members were having conversations over the phone whilst the perpetrator

of violence was in the home, rather than meeting the people we support separately outside in coffee shops as we usually would.