

Women's Health Strategy: Call for Evidence

Response from With You

With You is a charity that offers free, confidential support and treatment to people in England and Scotland who have issues with drugs, alcohol or mental health. We provide people with support in their local service, community or online. We are one of the largest providers of treatment and support services in the UK, with over 1500 staff and 800 volunteers, helping more than 100,000 people a year.

With You has been undertaking research exploring the experiences, and barriers to accessing health services for women who use drugs, often with multiple and complex needs. Through both quantitative and qualitative research methods, including a voluntary sector survey and literature review, centring front-line staff, managers and service users, we have compiled our findings and insights in this submission.

The women we work with are often marginalised, stigmatised, and forgotten about in health service design, in research and in policy making. They often have multiple and complex needs, including both mental and physical health requirements. We believe it is essential that a new Women's Health Strategy addresses the needs of this community.

Introduction

Women and men's experience of using drugs, in accessing support and in engaging treatment are very different. While trauma is a big factor in both male and female substance use, relationships with a partner play a much larger role in women's drug use. Women are more likely to be introduced to drugs by a partner, while men are more likely to be introduced by a friend. Women's use often begins out of "necessity", as a coping mechanism, whereas men are more likely to first use drugs recreationally. Women also progress from first use to problematic use at a faster pace, a process known as 'telescoping'.

Women facing homelessness, substance misuse and contact with the criminal justice system are also more likely to have experiences of abuse, violence and trauma and particularly poor mental health.

In England and Wales, according to the ONS, the female rate of deaths due to drug misuse has steadily been increasing for several years. The latest data show that although men account for two thirds of drug-related deaths, there has been a significant rise in women dying due to cocaine—up by 26.5% a year compared to 7.7% for men.

This is mirrored in Scotland, where drug-related deaths have increased significantly in recent years, with a much greater percentage increase in deaths among women than among men.

Accessing treatment can be a daunting prospect for women. Services are often male dominated which can be intimidating, especially if the woman in question has experienced abuse.

The impact of long-term disinvestment has also affected how services engage women. With local government budgets being subjected to concurrent years of cuts, the drug treatment system has experienced significant local variation as a consequence of some Local Authorities having reduced treatment expenditure by 40%. While some authorities have the resources to provide a whole range of services for women who use drugs, others do not have the capacity to do so.

Women's voices

Barriers to treatment and evidence on how current services do not meet women's specific needs

89% of responses to our voluntary sector survey agreed that women face additional barriers to accessing drug treatment when compared with men. Overall, we received 36 responses to our survey, including from a wide range of organisations such as Homeless Link, PAUSE, SafeLives, Release and Solace Women's Aid, amongst many more.

Below are some of the main barriers to open treatment and conversation identified through our research.

1. Male-dominated services can be intimidating for women

The majority of people in treatment for drugs in the UK identify as male. In our voluntary sector survey, male-dominated services was the most common barrier cited in response to the question – *what are the major barriers women who use drugs problematically face when trying to access treatment and support?* – with 43% of responses stating it as an issue. This experience is supported by interviews held with service users:

“Women disproportionately experience domestic violence and many are scared to attend services that may have busy waiting rooms with men and even potentially ex-partners. Several of my clients have avoided drug and alcohol services because they know that abusive ex-partners attend.” – Service user

Reception areas of substance misuse services have been regularly described as a risky area for women to enter, leading to reduced engagement with health services and preventing some women from accessing treatment.

Past experiences of abuse, or a need for female-specific health services have made male-dominated spaces a significant barrier for women. 64% of those responding to our survey believe drug treatment services do not place women's different needs and experience at the forefront of their policies and services, remaining sufficiently misinformed in aspects of gender.

In order to combat this, female voices must be acknowledged and centred within the health and care system.

2. Women feel intense stigma about disclosing their drug use

There exist many barriers to open and inclusive discussion for women who use drugs. Many women feel intense stigma about disclosing their drug use, often fearing being judged by those around them. Facing damaging taboos when wanting to start conversations about their health can make it difficult for women to speak to healthcare professionals, family members, friends or employers. Many women have described how the stigma of disclosing their drug use has prevented them from seeking treatment, and how their family members are often fearful about the stigma attached to someone in the family having a drug issue.

In our research, multiple service users, as well as front-line workers, raised stigma as a significant obstacle:

"We're not just going to immediately assume that because you use drugs that you're incapable of loving your children, it's about breaking down our stigmas towards females in service and understanding their unique issues." – Recovery Worker

Women can fear being stigmatised both within drug treatment services and by those outside of treatment. Further training and education for clinicians on sex and gender differences, and exploring the embarrassment and fear of stigma many women face, is essential to improving treatment and ensuring women feel comfortable accessing services.

3. Women with children in their care fear losing custody if they disclose their drug use

Women who have children face additional challenges in accessing services and often fear social services becoming involved if they disclose their drug use. PHE statistics reviewing treatment in 2019/20 show that 44% of women in treatment for opiates are parents who are not living with their children.

Service providers have identified the fear of losing custody as a significant barrier for women, often causing them to disengage with drug treatment, ensuring any health and care problems they face remain unresolved. Social services are also said to have a poor understanding of the process of addressing drug misuse:

"I was scared to say it to social work in case they removed my kids, so my girls went to my aunt on a voluntary basis. My experience with social services was I just felt there was support lacking there. I felt they could have helped me when I was trying to get into the crisis centre, alongside my addiction worker." – Service users

Fear of social services not only impacts women's access to treatment but also inhibits front-line workers' ability to develop trusting relationships with their clients:

Information and education on women's health

Evidence on the barriers under-represented groups of women face when accessing information, education or treatment

Women from the BAME community with an addiction are presented with additional anxieties and barriers to asking for help. Participant's highlighted that they were unaware of support in the community and the ones that did access local services, often had a mixed response to their engagement with these providers. Those that had positive experiences of mainstream support, noted there were usually few people of colour present.

In addition to fears of being misunderstood in regards to culture and beliefs, women from the BAME community often feel they have to 'fight to access services, justifying why support is required'.

A Muslim woman who sought support in a mainstream service spoke of her frustrations of the process:

"[The service] wasn't taking me seriously. I was treated differently... it was always about them and I was repeating myself again and again. It wasn't encouraging, I felt much more stressed going to these appointments."

Participants in our research acknowledged that cultural aspects and services being culturally orientated was important to them in terms of receiving tailored and holistic recovery focused support.

A questionnaire to four front-line workers who regularly offer support to women from the BAME community affected by problematic drug use, sighted the following barriers that these women face when accessing treatment and support:

- Shame guilt and ostracism from family/community
- Increased risk of domestic abuse
- Fear of judgement and not being understood
- Childcare responsibilities
- Fear of forced marriage
- Disconnect with mainstream services

Women's health across the life course

Evidence on how current services do not meet women's specific needs

Drug services miss opportunities to engage women around their drug use. In the voluntary sector survey we conducted, 60% of responses disagreed with the statement that *Drug treatment services are sufficiently gender informed* – with only 8.4% of responses agreeing with the statement.

Our research found that, on occasions, services can be inflexible and react insufficiently to women's needs, preventing them from accessing effective treatment. Women are often unaware of what support is available to them:

"I was in hostels for a year and a half and they never told me about drug support – they never told me. When the lady said would you go into rehab I said what's

that? I'd never heard of it. They don't offer you any kind of way out." – Service user

"There is a lack of cross-sector working and a lack of visibility in spaces that women are likely to inhabit. A lack of a gender-informed or gender-specific approaches/ consideration." Voluntary Sector Survey

In response to the question – *What factors can prevent drug treatment services from better engaging and supporting women who use drugs problematically?* – 28% of survey responses cited the issue of inflexible appointment times, with some responses describing treatment services as "rigid."

Opportunities for targeted action to improve women's access to services and evidence on the potential benefits

1. Female specific spaces help women engage in treatment

The majority of women from our research, including 89% of those responding to our survey, identified female specific spaces as a significant factor in engaging women in drug treatment and support.

Women continually described feeling more secure in segregated spaces as it allowed them to share more freely and forge foundational relationships with other women. Amongst other reasons, a greater understanding of women's specific experiences, including childcare and abuse, were cited in support of same-sex services. Some women reflected that female specific spaces allowed for gender-informed discussions and treatment, and also represented a safe space for vulnerable women:

"It was nice to sit in a group and identify with a lot of these women. Some women have lost their children; one of them is now my best friend... It was nice to be able to get feedback from other females that have been through similar things. There's a safety of the women becoming part of a team, if that makes sense. It's easier to share, some of the stories you hear in there you wouldn't hear it in a mixed setting. They're about rape, there was a young girl who was going through the court process with her child, there was another one who had got clean had a baby and then she started using and prostituting herself, women's issues." – Service user

2. Engagement in community settings can make women feel more comfortable

A move away from clinical settings can often make women feel more relaxed and at ease seeking treatment. One woman who accessed support outside a substance misuse service, described her experience:

*"I felt like I was at home. It's a lot easier than going into the building when you are on methadone you need to have your urine tested – but going in would make me so anxious all I used to think about was going to get a drink which would set me off. Meeting at *** really made a difference." – Service user*

The idea of engaging women within non-clinical settings was also highlighted by substance misuse commissioners as a key method for improving women's access to health services:

"The best practice for engaging women is through outreach in the community; drug and alcohol buildings can be a big deterrent. Having drug support embedded in community environments is key, so we are addressing the whole and not just the substance use." – Substance misuse commissioner

Multiple women agreed that being offered different treatment options increased their chances of recovery, and having a choice in how and where meetings were conducted was crucial due to their past traumas.

3. Access to mental health support helps women come to terms with past trauma

Multiple women interviewed praised the impact that mental health support had had in helping them engage with treatment and reduce or even stop their drug use. Some went on to detail how access to mental health support helped them come to terms with having children removed from their custody.

"I had 10 months of counselling which changed my life. I was a sex worker as well – I had a lot of stuff that needed healing. I used because of trauma... I needed to work through all that stuff and go through it all not to relapse. It made me see the truth in everything. The counselling went through childhood stuff, relationships, around my past and what I'd done. It was really difficult going through it. The ten months I was doing it was a really dark place, but I didn't use and I kept going back." – Service user

Stretched and underfunded services mean many drug treatment services cannot offer mental health specialisms as part of treatment. Additionally, women who are actively using drugs are often barred from accessing NHS mental health support, which can leave the underlying issue behind a woman's drug use unaddressed.

4. Women cannot always access the level of support they want due to stretched services and high caseloads

Women with multiple complex needs often require intensive support which under-funded treatment services struggle to provide. As part of our research, many women highlighted how inconsistent support leads them to disengage with treatment. Front-line workers also commented that high caseloads meant they simply did not have the capacity to provide each client with additional support.

"I bring the sex workers in every other week to get their script and ring them on the opposite week. Spending that amount of time with someone is like putting a sticking plaster on a gunshot wound." Recovery worker and sex worker lead

"I think one of the traps that we fall into is thinking seeing someone once a week is enough. It's a drop in the ocean. They have an ongoing life outside of us and really once a week makes little or no impact." Regional manager

Increasing the flexibility of drug services for women, reducing caseload numbers so more time can be spent with women, increasing the frequency and duration of sessions with service users, would reduce their barriers in accessing health and care for specific needs, and allow them to meet multiple and overlapping needs in one place.

5. Some women find it easier to engage with treatment online

Many women interviewed described how they find it easier to engage with drug treatment digitally, particularly when feeling unmotivated or burdened with multiple responsibilities. Between May 2020 and April 2021, 63% of people who stated their gender when accessing support via With You's online webchat identified as female:

"When you access support online you can present what you want, you don't need to organise childcare. Whereas, I think if you come to that face-to-face service, they're worrying that... there's someone they know sat in that room." - Recovery worker and webchat advisor

It must be noted, however, that in spite of this, 75% of responses to the voluntary sector survey agreed with the statement that – *the coronavirus pandemic has made it more difficult to engage, support and retain women who use drugs problematically* – with a consensus that clients with multiple complex needs often struggle with digital tools and benefit from face to face support.

Moving forward, a dual approach which provides women with a choice, allowing for in-person meetings as well as digital services, would be most impactful.

6. Peer mentors are crucial in engaging and supporting women

Many women interviewed stated that peer mentors played a crucial role in their recovery:

"People that were volunteering for With You... gave me some hope, strong women that believed in me before I did myself and helped me grow. They did it in such a kind and caring way, seeing others who had got sober and not gone back to using – that really uplifted me and showed me it was possible." - Service user

The ability to connect with others who have similar experiences and backgrounds was particularly prioritised by women from the BAME community:

"[In accessing culturally specific groups], I feel like I am heard and have hope and encouragement and people can help me from my background and who understand me." - Service user

Research, evidence and data

Aspects of health or medical research that overlooks or neglects women's perspectives or experiences

Women are traditionally underrepresented in data and research around drug use and drug treatment. Drug use and problems unique to women have received insufficient attention in research and there is also a lack of female scientists investigating the issue.

Men are more likely to be present in specialist treatment, and research is often reliant on male samples. Too often, service design is based on the needs of male service users.

There are many complex reasons why women develop an issue with drugs. Below is a summary of the key themes we have identified.

1. Many women who use drugs have experienced early trauma

There is a direct correlation between early trauma and drug misuse, with people often using drugs to self-medicate mental health issues that stem from adverse childhood experiences and general trauma. Our research found this to be particularly true for women. Women often cited parental substance misuse as a factor in their own drug use:

"It all stemmed from childhood, I had a very abusive family. A lot of sexual, physical and mental abuse. I went into care at 5 or 6, it was alright for a while. Mum died at 8, she was a heavy drug user. As I got older, I was abused a bit in care. Social services tried to move me to Ireland and that just didn't work for me. I started self-harming at the age of 11 then moved back in with foster parents in Bournemouth. They couldn't deal with me, so I was passed around foster home to foster home." - Service user

These testimonies were supported by front-line workers who specialise in supporting women, with some professionals revealing that traumatic experiences can make it harder for women to engage with services.

An approach tailored specifically to female experiences is therefore vital if we hope to see an improvement in their access to health and care.

2. Abusive relationships play a major role in female drug use

2016 research by Agenda, the alliance for women and girls, found that women who have experienced domestic abuse are eight times more likely to develop a problem with drugs than women who haven't. The findings of our research support this, with the majority of women interviewed reporting experiences of abusive relationships:

"Domestic violence was part of every relationship I went into because I had no idea how to have a healthy open relationship. Eventually I picked up heroin and crack." - Service user

Agenda's 2016 research also found that women are more likely to start using drugs with a partner, while men are more likely to first use with friends. It is clear that women in controlling or abusive relationships are often prevented by their partner from accessing support around their drug use. In our voluntary sector survey, the second most cited barrier preventing women from accessing drug treatment was the impact of domestic abuse, with 37% of responses raising this.

The Head of Services at a domestic abuse charity explained how controlling relationships can prevent women from accessing support:

"I think for most women in that situation, there will be no way of accessing services because oftentimes, their freedom is so limited that for them to go and access support would be almost impossible. And those who are still dealing with the perpetrator, whether or not they're even considering leaving, for a lot of them,

their drug or alcohol use is the only way they can cope."

3. Losing custody of children can lead women towards riskier behaviours

Recent research by Tweed, Miller, Schoefield, Barnsdale & Matheson¹ exploring why female drug related deaths are rising in Scotland, found that women who have experienced losing multiple children often have few positive family relationships, stating that losing children can contribute to "re-traumatisation, hopelessness and risky consumption."

The findings of our research support this, with multiple women interviewed describing feelings of hopelessness and increased drug use after having children removed from their care. For women who have had multiple children removed, they often reported increasing hopelessness and drug use after each incident.

"First three weeks [after losing children] I hit the drugs hard, drinking a lot again. I smoked heroin which I don't normally do." - Service user

Impact of covid-19 on women's health

75% of those responding to our voluntary sector survey believe that the Coronavirus pandemic has made it more difficult to engage, support and retain women who use drugs problematically in health services. The most common obstacle, cited by 28%, is a drop in face to face services. Women have found it increasingly difficult to engage with services virtually which has limited their access to support. One respondent notes that hub workers holding home visits have been in higher demand amongst female clients in comparison to online/digital services.

Other negative implications of COVID-19 on women's drug services includes technological difficulties and restricted access to phones/tablets, fear of abuse for women living in unsafe environments, and also the overstretched nature and reduced capacity of drug treatment services/providers.

It is important to note that 11% of respondents to our voluntary sector survey do not feel the pandemic has made a difference to women's access to drug treatment. Indeed, they believe that services have become far more accessible and flexible with the rise of digital sessions/appointments, often noting it's positive implications on childcare.

A dual approach to drug treatment, including both digital and face to face services, would be most impactful in engaging women moving forward.

Key recommendations

In order to improve women's access to health and care services and reduce the disparity between men and women in accessing treatment, the Women's Health Strategy must do the following:

¹ Tweed EJ, Miller RG, Schofield J, Barnsdale L & Matheson C (2020) Why are drug-related deaths among women increasing in Scotland? A mixed-methods analysis of possible explanations. *Drugs: Education, Prevention and Policy*.
<https://doi.org/10.1080/09687637.2020.1856786>

- **Adopt a cross-departmental and gendered approach to addressing the needs of women who use drugs and have multiple complex needs;**
 Policy interventions to reduce drug-related harm sit across government departments and therefore there needs to be improved cross-government action through a joined-up drug policy programme between all relevant government departments.
- **Improve research and data collection to ensure women are not underrepresented;**
 As a community with significant mental and physical health needs that are often underrepresented in research, data, service design and policy-making, it is imperative that women's voices and specific experiences are central in the making and implementation of health policy. Data collection must document female experiences of trauma, abuse, childcare, homelessness, etc, as well as experiences of women from the BAME community.
- **Deliver an ambitious multi-year funding commitment for substance misuse services in the upcoming Spending Review;**
 This long-term disinvestment of local drug treatment services has resulted in the closure of gender-sensitive services, higher thresholds for accessing support, and reductions in staff pay and experience.
- **Address the role of abuse and violence against women and its impact on drug use and mental health;**
 Greater focus must also be on ensuring service users can access mental health interventions within a substance misuse setting beyond CBT.
- **Involve women with lived experience in service design, delivery and evaluation;**
 Services are often designed around the needs of male service users. Involving women with lived experience in both the service design and commissioning process is vital to ensure the specific and unique needs of women service users are being met.
- **Design specifically for women; Ensure service branding and marketing is visually engaging for women and that their physical spaces are flexible, appropriate, welcoming and engaging;**
 The branding of services is very important and presenting a service as a health and wellbeing service. Services should also provide women with the choice of where and when treatment is provided, particularly for those with experiences of trauma.
- **Deliver female specific interventions, such as women's group meetings, assessments, key-working appointments, and other interventions, in community settings;**
 Having drug support embedded in community environments is key so that the overlapping needs of women, not just substance abuse, are addressed. Local services should ensure female-only spaces are provided in community settings, including access to key-workers and all female groups.

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