Listening to the stories of women who have experienced child removal due to drug and alcohol use

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Maternal Mental Health Alliance

REFORM
Improving outcomes for mothers at risk of child removal

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Introduction

For many years the public sector has been seeking to make the healthcare system work better for everyone and this is especially true for maternal mental health. Developments, such as the roll-out of specialist perinatal mental health teams across the UK, strive to better support all women, babies and families at their time of need and to intervene for women in ways that are both effective and efficient.

Over recent years, women's voices are being increasingly heard within the context of the transition to motherhood, and the mental health implications that come with this. However, although seldom listened to voices, such as those of Black and brown mothers, are being heard more loudly (albeit still not enough), there remain groups of women for whom, there is still a significant lack of understanding within the sector and more widely.

The findings of the annual MBRRACE report (which looks at women who have died during pregnancy or the 12 months after they give birth in the UK) persistently flag up the very high risks to women facing multiple adversities. This group are disproportionately represented in the numbers of women who die, particularly by suicide or overdose. It is further worth noting that most of these women do not have a diagnosed mental health problem but do have a history of trauma.

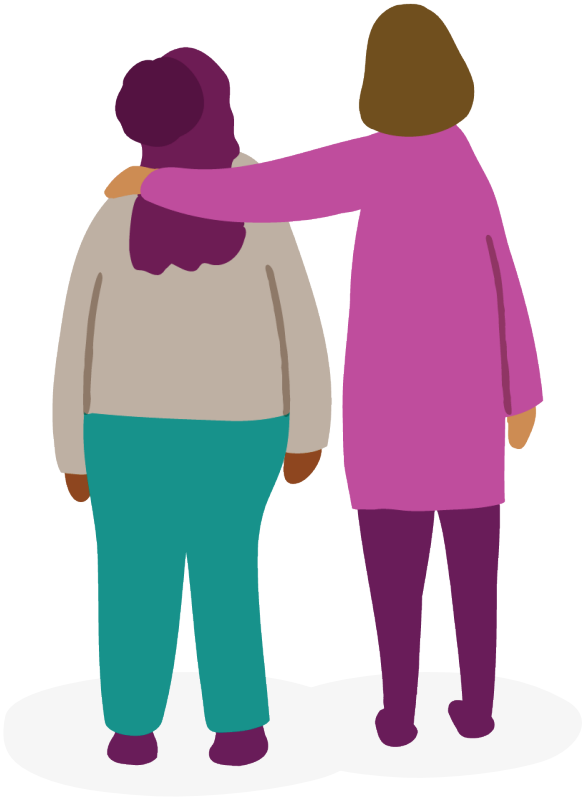
For women facing drug addiction, there is an intense stigma around pregnancy, birth and the postnatal period. Some mothers face the trauma of having their children removed, whilst others are unable to access the support that they need to manage their own mental health whilst also caring for themselves and their children.

This is often the most judged group of women.

This Listening Project was born out of a desire to listen to these women's stories. We believe that listening to women's experiences is the only way we'll find out what's not working, discover what will and take action in ways that address the root causes of injustice and exclusion.

Methodology

The ethos of the Listening Project is based on an agile listening process. In the initial development of the project the importance of allowing the women to lead the conversation was acknowledged. There was intentionally no clear set agenda, instead recognising the importance of being 'led' by the conversations.



There is no formally regulated practice of listening, especially when related to trauma awareness, however insight was drawn upon by the 'Learning to Listen' research developed by the CPI in the aftermath of the Covid-19 pandemic. The key components of the exercise were to build trust, engagement and agency, allowing the participants to feel they were part of the development process.

At an initial stage, the Maternal Mental Health Alliance (MMHA) were able to connect with REFORM, a trusted organisation, who have developed significantly positive and trusting relationships with the women they support. After explaining our initial thoughts of the Listening Project to staff, we were connected with three women who it was felt were in a stage in their recovery where they would be able to engage with the project in a safe and productive way.

An initial meeting took place between the MMHA CEO, MMHA Lived Experience Coordinator, Women's Reform CEO and the three potential participants. During this meeting we shared our initial thoughts for the project, whilst making it clear that we were open to suggestion.

One change that came about because of this meeting was related to the structure of the conversations. Whilst the women acknowledged the importance of allowing the conversation to be led by them, they also suggested that having a set of prompts or questions to guide the conversation could be supportive and encourage feelings of safety.

The women were encouraged to take some time to consider whether they would like to proceed, being made aware that they could withdraw at any time. Following this, we met once again to talk through what the women would like to be asked, allowing for noting individual preference. Once a list of prompts was drafted, these were then shared with the women for approval.

Individual conversations were scheduled at a time that was convenient for the women being interviewed. One of these took place in person and the other two were virtual.

All of the women received financial compensation for taking part and emotional support.

Key findings and insights

THEME 1.

History of mental health struggles and challenging life events and the struggle with dual diagnosis

"I used drugs for support, because there wasn't anything else there for me."

At the core of these stories, was the impact of a lack of suitable mental health care for those women who needed it. Dual diagnosis is a term used when someone experiences both mental health difficulties, alongside issues with substance abuse (drugs and/or alcohol).

Traditionally, services have been set up for people to support either/or - either the mental health problem, or the substance abuse. However, these issues are so intertwined that the lack of a sustainable service that supports both can be incredibly challenging.

All the women who we spoke with discussed mental health difficulties that existed long before pregnancy. Some had a formal diagnosis e.g. personality disorder, generalised anxiety disorder, bipolar, whilst others also spoke of general low mood, self-harming behaviours. The lack of early support and the subsequent impact is significant.

Indeed, the reason that many of the women turned to drug use in the first place, was to cope with their poor mental health. Often, this drug use started at a young age, following an emergence of mental health difficulties during childhood.

With the above acknowledged challenges of dual diagnosis, one of the women reported that because of her history of drug use, it was years before she was offered medication to treat her depression. She has only this year started taking antidepressant medication, something that she reports finding extremely helpful so far. She first reported symptoms of depression fifteen years ago.

The women who we heard from spoke about struggles with their mental health going back, at times, many years. The women told stories of past trauma and adverse life events, including mental health difficulties starting in childhood to early teen years, domestic

abuse, traumatic relationships and unstable living arrangements. Histories were described as “chaotic”, “messy” and “tricky”, with all the women misusing substances prior to the pregnancies, often as a means of coping with poor mental health. Frequently, this was due to there being little to no support for their mental health available at the time.

One woman shared that she “used drugs for support, because there just wasn’t anything else out there for me. I was never bad enough to be able to access any services and so just tried to cope on my own”.

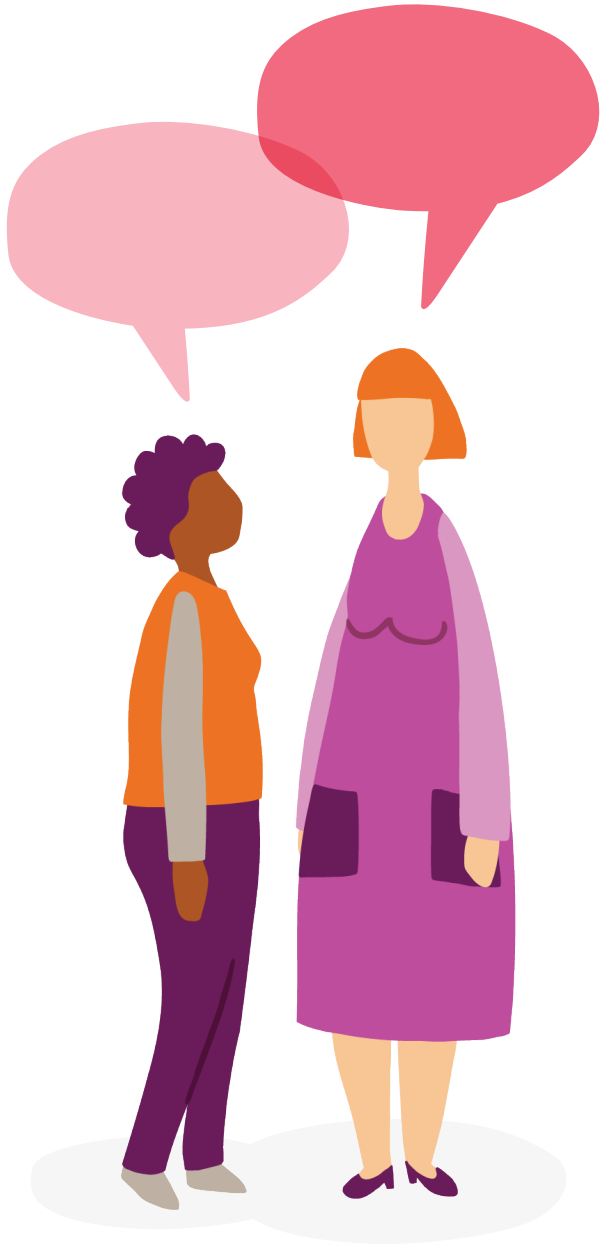
With all, there was a desire and a hope for stability, with some of the women speaking of how they’d hope that pregnancy marked a new start for them.

“I thought that having a baby would mean that things would settle down and everything would be brilliant, and we’d both get jobs and have a house to live in. But it didn’t work out like that.”

“The focus was always on the substance use, never my mental health. But I used drugs because my mental health was the way it was.”

As MMHA’s strategy notes, ‘We know that experiences of trauma have a pervasive effect on a person’s mental health, and this is exacerbated in the perinatal period’.

The perinatal mental health sector has begun to recognise birth trauma well, but this is not always the case for childhood and current trauma outside of the birth experience. A lack of understanding of the crucial links to poor maternal mental health results in missed and lost opportunities.



THEME 2.

Mental health support during pregnancy

"No-one ever asked."

Linked to a lack of appropriate mental health support prior to pregnancy, was a lack of compassionate mental health support during pregnancy and following the birth.

The women spoke about feeling "invisible" as a mother, with a persistent feeling that they "mattered less than the baby". Although all the women spoke about understanding the reasoning behind this it did not take away from the pain that it caused.

"It becomes all about the child, and the risk to the child, which I completely understand but there's more to it than that, isn't there? I was the one carrying the child. Didn't I matter too?"

This is despite clear guidance that all women should be asked about their mental health at each routine antenatal and postnatal contact. The need for compassionate care, and connection was noted by all the women, as well as a deep desire to be seen as a whole person with one woman sharing "There was no depth of knowledge about who I am as a person, or an interest in finding that out." For one of the women, the pregnancy felt like a "missed opportunity" for support to be given, at a time when it was most needed.

"Nobody said to me 'this could be a really important time for you to get some support'. I said early on that if the best thing for my child was to be removed then that's what I want to happen because I want my child to have the best start in life and I can't provide that for them. Perhaps someone could have said 'oh god this woman feels so bad about herself that she doesn't even think she can be a mother'. I couldn't see that in myself, and nobody helped me to see that."

Another woman shared that throughout the entire pregnancy she kept hoping that someone would ask her what she wanted, but this question never came.

"I wanted desperately for someone to ask 'what do you want out of this pregnancy? This is your child, you're the mother. What are your fears.' No-one ever asked."

The theme of there being a distinct lack of acknowledgement of the importance of maternal mental health was there for all the women, with none of them being signposted towards mental health services or being offered education advice around maternal mental illness. This was despite there often being a recorded history of mental health difficulties.

"It was on my record that I'd had depression before, but no-one spoke to me about being at higher risk of developing postnatal depression."

A lack of consideration of past trauma was another frequent theme.

"No one ever asked about my past, my history of trauma, my ACEs (Adverse Childhood Events). No one put all that together and got to know me."

For some of the women, the pregnancy journey felt "clinical" at times, with one woman describing it as feeling as though she was "on a conveyor belt" and this impacted on their sense of self-worth.

"They just wanted to know if I was using. They never asked how I was feeling, or, if I had used, why I'd done it. It felt like I didn't matter."

This lack of acknowledgement of the need for mental health support continued post birth. One woman shared that after her baby was born and subsequently removed from her care she was "no longer treated as a mother" and no information on maternal mental health was shared with her.

In keeping with the theme of there being a lack of consideration of the mental health impact, one woman shared that no-one explained to her what postnatal depression was, despite experiencing significant low mood and other symptoms that aligned with that diagnosis.

"Even though I told them how I was feeling, no-one said 'you can get that [PND]. Even if your child's been removed, you can still get that."

Another woman shared that:

"looking back now, I just needed a little bit of advice, you know, a little bit of support. If I'd understood what postnatal depression was that might have helped. Although I felt very mature at the time, I wasn't. I was still a child."

Finally, it was simplicity that was often missed. Although complex past histories can require intense levels of professional support, it was sometimes simple, compassionate care that was craved.

"The first few weeks after the birth were really hectic. I just would have liked someone to check in, to see how we were doing as a little family. Take us for a coffee. Ask how I've been feeling."

Stigma and Shame

"It felt like I was the only one going through this."

The need for mental health support, understanding and compassionate advocacy could have gone a long way to remedy the pervasive stigma at the heart of many of these women's experiences.

Common themes of feeling judged, misunderstood, shameful and guilty were spoken of frequently, and the feelings of judgement were sometimes seen from the healthcare professionals working with them.

One woman spoke about there being a lack of acknowledgement of the efforts she was making to keep herself and her child safe and well.

Another woman shared that throughout her pregnancy, she felt that she was treated very differently from other mothers, with her needs and feelings dismissed.

"I remember showing the social worker my birth plan, that I'd spent a long time thinking about and researching, and she just laughed. I felt invalidated."

This was something that another of the women that we spoke to experienced after giving birth.

"I remember feeling really judged by the midwife that came around after I gave birth. The bedroom upstairs felt too cold for the baby, so I moved them downstairs where it was warmer. When she came round, she just looked at the mattress on the floor. I kept trying so hard to do the right thing, but it never seemed to be good enough."

It is well recognised within mental health care that early intervention is key to a promising recovery, and that stigma and shame often keep people from speaking out sooner. The creation of an environment where someone feels they must keep hidden some aspects of their experiences is not conducive to recovery and can lead to a significant worsening of mental health and, in some cases, may even have prolonged their reliance of substance misuse.

"Some of the stuff that I couldn't share kept me ill for even longer. I could never be honest about what was going on for me because the consequences [potential child removal] were so huge."

"You feel such shame, like you're the only one going through this. And because of the guilt and the shame I tried to end my life. I blamed myself for everything."

The need for investment in advocacy

"It felt as though there was no-one on my side, fighting for me."

When speaking of what was needed, the women spoke about the need for advocacy and better understanding from Healthcare Professionals (HCPs) about drug and alcohol use and social services input.

One of the mothers described a "huge lack of empathy and understanding" around substance misuse and social services input, which means that compassionate advice and guidance around the process of working with social services is often missed. One woman described finding the process:

"so complicated and draining" and that "I just wanted someone to guide me, and tell me that things were going to be okay, however they worked out."

All the women spoke about feeling the need to advocate for themselves. This was in part due to a lack of awareness of some of the HCPs they encountered, meaning they had to solely self-advocate. They shared that they "had to do all my own research, at a time when my head was so full. People need to know their rights and understand the process and be educated about what might happen." In other situations, it was a lack of consistency and an inability to build a relationship with one person that led to them feeling isolated and alone.

"I think I saw around five or six different midwives, each time I had to explain my situation to them. No-one ever got to know me. Being able to have a consistent relationship with someone who would advocate for me would have been so helpful. Someone who knew me and could say to others 'hold on, this person isn't just a drug user'. They could have helped me to see that too."

The women spoke of wanting people to walk alongside them, encourage them to consider their role as mothers, what they wanted and what they felt was achievable.

"People need to be asked – what do you need to get through this process, and then not just asking the question but really giving me the time and space to think about the answer."

The importance of advocacy also took on a very clear meaning when involving other women with lived experience of addiction and involvement with social services.

"There needed to be a focus on peer led lived experience advocacy. Women who've been through child removal. Who'd said, 'we'll come with you to a meeting', or 'we'll ring you to check how you're doing' or 'I'll come with you to an appointment'. That would have made a huge difference."

THEME 5.

The importance and impact of effective peer support

"Talking to others takes away some of the shame."

When sharing what has been of particularly high importance to them, as well as what felt lacking at the time, the importance of peer support was clear.

The women spoke of feelings of isolation and "otherness" throughout their stories, along with an unshakable feeling that they were "the only one". Even the one woman who attended baby groups shared that she felt "different" from everyone else that she met.

"I went to a few groups, but I just felt 'less' than everyone else, you know. Being a teenager with a child felt so different to the other women I saw there. Of course I wasn't the only teenager to have a baby, but at the time it felt like it."

The power of being able to openly share experiences and feelings, without shame or fear of judgement was felt strongly through all the testimonials. Connection within mental health is a theme that is of growing importance, and this was clearly expressed through the women's stories.

"To get your child removed for me still feels like a whole different level of failure, so to speak with other people who have been through that... it matters so much."

One woman shared how "talking to others takes away some of the shame" and the importance of being able to connect on that level. Her only regret is that she was not able to access a space like the one she does now any sooner.

"The women's group I go to now, talking with others who have been through similar things, it makes you feel less lonely and more hopeful. When I started going, I finally felt like recovery was possible."

Creating a space where it is possible to share these stories does not happen by accident, rather through the careful consideration of many elements by the facilitators, from physical environment to group agreements.

When all of these are in alignment, it creates a space where the women feel encouraged and able to share to the level they wish, as well as provide mutual support to those around them. In the words of one of the women, "you just feel so safe."

THEME 6.

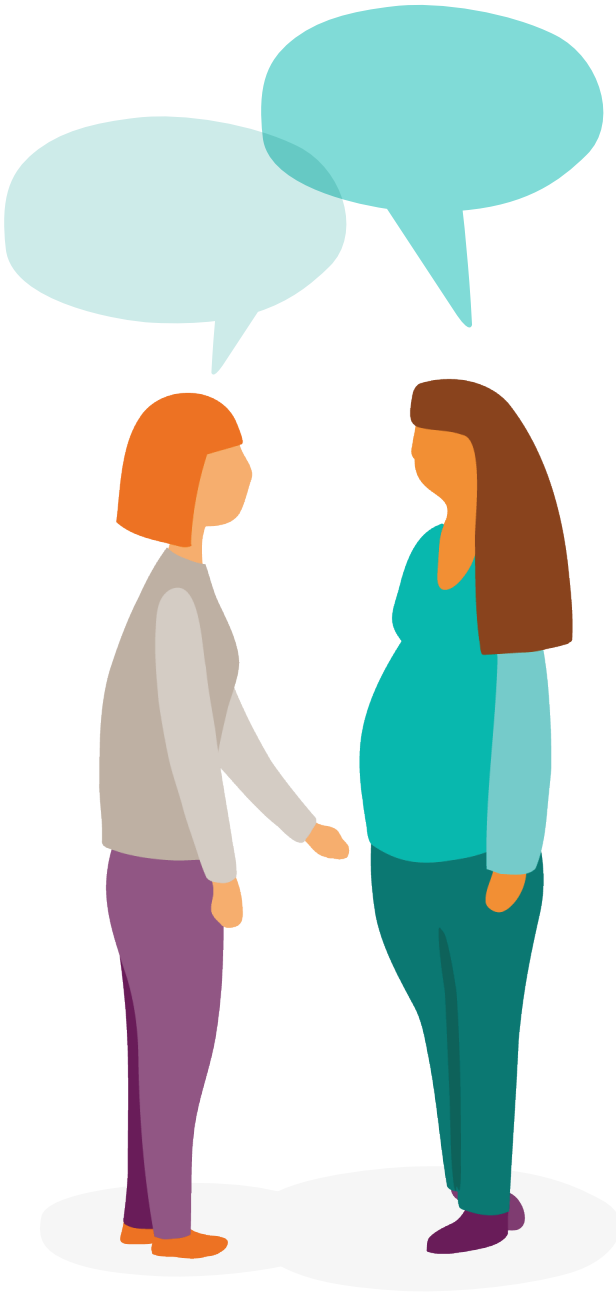
Hope

“It was when I spoke to the women who were in my recovery group, that I knew that things could and would get better for me. I felt hope for the first time in my life.”

Finally, and most importantly, it would not be right to share these women’s findings without also speaking of the role that hope plays.

Each one of these women is now in recovery. Throughout the conversations, they spoke of wanting to help others who may find themselves in a similar situation. That they can take the trauma they have been through and turn it into something that may help countless others should not be underestimated.

The strength, persistence, empathy and courage they show in sharing their stories ought to be deeply valued, as should their role as women, as supporters of their peers and, most importantly, as mothers.



Recommendations

Following the conversations and analysis of the above key themes, two key recommendations have been identified. These are at an early stage and largely relate to acknowledging the importance of further research in each area.

Whilst some actions have been taken which start to recognise the gaps within care for new and expectant mother, for example NHS England supported a good practice guide on trauma-informed care in the perinatal period and a small number of Maternal Mental Health Services support women experiencing loss through care proceedings, many of the themes which came up in these conversations directly link to recommendations the MMHA has made from other pieces of research. This includes education and training for healthcare professionals, a need for a trauma informed approach and a linked up system across voluntary and statutory service. Demonstrating further action is needed across the UK to better support the needs of this group of women.

Recommendation 1

Training on mental health and trauma awareness, including drug and alcohol use and dual diagnosis is essential for all healthcare professionals who meet women on their maternity journey (e.g. GPs, midwives, health visitors).

The lack of understanding of mental health, trauma and substance misuse from many of the professionals who met with the women throughout their perinatal journey was notable.

For health and social care professionals to effectively support women in the perinatal period whose lives have been impacted by substance misuse, they must be given a working knowledge of the emotional and physical causes and impacts of mental health and addiction, as well as the various pathways and support available to these women, babies and families.

This training needs to be coproduced and delivered with women with lived experience, to accurately reflect the true experiences of those involved.

Recommendation 2

Further research into advocacy programmes and early-stage peer support for pregnant women with a history of drug and alcohol use.

There was a notable lack of effective support for women experiencing drug and alcohol use in the perinatal period, combined with an acknowledgement of the need for contact with people who have been through similar experiences. Both advocacy and peer support were highlighted as meaningful interventions.

Further research is desperately needed, within the wider body of work looking at effective mental health support for women with children's services involvement in the perinatal period. This must look into the specific needs of women experiencing addiction, including the value of advocacy programmes, when provided alongside social services input.

In addition, the significant impact of peer support was acknowledged by all the women. The positive influence of being able to speak with others who have experienced similar pathways was clear and is already recognised by services in the commissioning of peer support workers within specialist teams. However, there is a lack of existing research on the wider experiences of women with addiction issues engaging with this support. As with advocacy, there is significant merit in considering whether additional research could highlight potential new care pathways.

Conclusion

We know that drug and alcohol addiction affects women, children and families throughout the UK, yet the extent of the reality is difficult to quantify. A lack of published research and statistics on the impact of addiction on women and their experiences of pregnancy and motherhood is notable and it remains an area where women's voices struggle to be heard.

Models of effective support do exist through organisations such as REFORM, and for those women who can access these services, the impact can be life-changing, however there are far more gaps that exist, particularly during the perinatal period. Research into how to expand and amplify effective and sustainable support is limited and this must change.

It is through listening to the realities of people with lived experience that we can begin to understand what is truly needed, from connection and education to non-judgmental support. Only from a position of compassion and understanding can we then begin to influence future decision making on how to best support others who find themselves on similar paths. Women who have experienced addiction must be central to the conversations about the changes needed: their knowledge, empathy and strength deserves acknowledgement and their voices must continue to rise.

Acknowledgements

We are hugely grateful to REFORM for being open to their involvement in the Listening Project at an early stage. We would like to thank them for enabling us to reach the women we have spoken with and supporting them throughout their involvement in the project.

We are also hugely grateful to the staff at Ridley Villas for allowing us the use of their communal space for the conversations to take place.

Finally, and most importantly, we are deeply grateful to the women who took part in this project and shared their stories with such insight, authenticity and strength. Your compassion, empathy and hope for the future shone through and we hope that this report does justice to your words.

Maternal Mental Health Alliance

International House
12 Constance Street
London E16 2DQ

info@maternalmentalhealthalliance.org
www.maternalmentalhealthalliance.org
@MMHAlliance

Illustration by Carys Tait: Carys-ink.com. Document designed by White Halo Design.

Maternal Mental Health Alliance