



## Making Better Births a reality for women with multiple disadvantages

A qualitative peer research study exploring perinatal women's experiences of care and services in north-east London

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## Birth Companions

Birth Companions is a charity that has worked to support perinatal women facing severe disadvantage in prison and the community for the last twenty years. The organisation was set up in 1996 to offer birth support to women from Holloway Prison and services were developed subsequently in other prisons, and in the community in North East, North Central, and South East London. We work in partnership with maternal health services (including midwifery teams at the Whittington, Homerton and UCLH), other statutory services and the voluntary sector to deliver holistic, trauma-informed support that encompasses flexible, accessible and needs-led care, trust-based relationships, support and postnatal support that extends beyond midwifery care.

### Our current offer includes

- one-to-one support from specialist volunteers throughout the perinatal period;
- continuous doula birth support;
- breastfeeding support;
- targeted antenatal and early parenting classes;
- a mother and baby group;
- peer support;
- provision of essential practical items.

We also have a strategic role in commissioning and disseminating research into the needs of perinatal women facing severe disadvantage, and in shaping local and national policy that impacts on the care women receive.

## Revolving Doors Agency

Revolving Doors is a national charity that has been working for 25 years to change systems and improve services for people facing multiple disadvantage and stuck in the revolving door of crisis and crime. We bring independent research, service evaluation, policy and lived experience together to support effective solutions for the 'revolving doors group' of people. These are people who face multiple crises, including mental ill health, substance misuse, domestic abuse, homelessness and criminal justice contact.

We work to reform services, and improve support and outcomes for this group. We do this by working with policymakers, commissioners and service providers and through reflecting lived experience in everything we do. To ensure this, we have a national and regional network of forums of experts with lived experience. We act as a trusted "critical friend" to government departments, local authorities and service providers across the public and voluntary sectors.

Revolving Doors has a track record of involving people with lived experience in commissioning and in research. On behalf of the Ministry of Justice we developed and tested effective involvement methods for prisons and probation services. We facilitate the Lived Experience Team to the Liaison and Diversion National Programme Board at NHS England, ensuring lived experience is embedded in programme governance.

# Foreword

**Kate Brintworth**

Head of Maternity Commissioning for East London

All women having a child should have the opportunity to experience this most profound of human events in the most positive way possible. Sadly, what this important report shows is that this is still not the case for every women, and that maternity services still have much to do to ensure that whatever her situation, the woman is truly placed at the centre of her care.

The overwhelming voice that is heard in this report is the powerful and simple wish of women to be treated kindly, with respect and thoughtfulness; fundamental tenets of good care. When this has happened the difference it makes is huge, and it is heartening to read the stories of women being supported and helped with compassion. However, within this report there is also a strong sense of fear which must make us pause and reflect on how we are approaching some of our service users. No woman should come our services afraid of being judged, excluded from decisions, or having their confidentiality breached, regardless of circumstance.

It would be a mistake however to categorise this as being solely about how we make women feel. We know that women who face disadvantage and their babies are more likely to have poorer outcomes, so this work is one that has important safety implications. Much as we quite rightly spend time researching the optimal safe care delivery for women with a range of physically based care needs, it is vital we do the same for women whose lives are characterised by challenge and complexity from any perspective, including social and psychological.

This report does just that by offering us insight and recommendations on what women facing disadvantage need us to do to help them based on the insights of the women themselves. These insights and stories were given with trust, from women currently experiencing difficulties to women who had themselves previously experienced disadvantage. Such an approach offers an unparalleled opportunity to hear and report the lived truth for those women. That quality and power is one of the many reasons I feel so privileged to support, and to now recommend this excellent report to all those involved with maternity services.

## Peer researchers

As the group of women who undertook this research, we are pleased to write the foreword for this report. We are all passionate about improving the support that women and their children receive. Taking part in this project was important to us because we wanted to use our own experiences to help change services for the better.

We are proud of the work we have done, and of gaining the trust of the women we spoke to about their experiences. At times we felt emotional, but we were rewarded at the same time knowing that women were not living in silence anymore. The women we spoke to were able to feel and see that they could talk about issues safely with us as we had often experienced the same problems, such as domestic violence, substance use and homelessness.

This has been an amazing experience and we look forward to seeing the findings turned into real action. We want to ensure the stories and insights they have shared are heard and acted upon. We also want to thank each and every woman who shared her story with us.

To sum up with a quote from one of us: "The peer research training was where I realised for the first time that we were not just a group of women who wanted to find out more but we shared something. This 'something' was special".

## Acknowledgements

This work would not have been possible without the involvement of several organisations based in Barking and Dagenham and in Hackney who supported us to recruit women for this research, and who shared their expertise and insights with us in the process. We offer our sincere thanks to the following organisations: Excel Women's Centre, Playbus, Shpresa, Pause Hackney, Westminster Drug Project/The Orbit Centre and Choices Islington.

Particular thanks to Lesley Dixon and Donna Peters from Revolving Doors Agency's involvement team and to Kate Chivers from Birth Companions, whose contribution was vital in supporting the peer researchers and facilitating their involvement.

Many thanks to all the peer researchers who chose not to be named. Every peer researcher was an integral member of the team, and each woman's individual contribution made this research stronger.

## Executive Summary

Despite growing evidence that women facing multiple disadvantage experience significantly poorer outcomes and are worse served by maternity services, the concept of multiple disadvantage remains under-explored in maternal health research and policy.

The aim of this research is to understand better the experiences of perinatal women facing multiple disadvantage who access care and services in north-east London; and to ensure that the findings support the transformation of maternity services in Hackney, Barking and Dagenham, and across the East London Local Maternity System.

This research was led by women with experience of multiple disadvantages – peer researchers - and was co-designed with local commissioners. It gives voice to 34 women whose views and insights are rarely heard by mainstream services. Their experiences included domestic violence and abuse; mental ill health; substance misuse; homelessness; significant, concurrent or recent trauma<sup>1</sup>; trafficking; criminal justice contact and the removal of children into the care system.

Some 20 findings emerge from this research and are detailed in this report. The overarching themes were: fear and distrust of services; the need to ask women more about their situations in order to better understand their specific needs; a swift response to problems and early, proactive referrals; the importance of a compassionate and non-judgemental approach; the value of continuity of carer, specialist midwives and ongoing support post-birth. The research identified the severe financial hardship women experienced in the perinatal period and the high prevalence of recent or concurrent trauma that impacted on women's ability to engage with support. Understanding and responding to the specific needs of recent migrants, asylum seekers, women who don't speak English, BAME women and other groups was also critical.

The perinatal period is one of great opportunity when, with the right support, families can make changes in their lives in order to improve outcomes for themselves and their babies. During a time of transformation in maternity services, this evidence is particularly valuable in informing services trying to adapt to meet the increasing needs of the most marginalised women and their babies.

## Introduction

In 2016 NHS England set out a vision to transform maternity services in England over five years in its *Better Births* report:

***“Our vision for maternity services across England is for them to become safer, more personalized, kinder, professional and more family friendly; where every woman has access to information to enable her to make decisions about her care; and where she and her baby can access support that is centred around their individual needs and circumstances<sup>2</sup>.”***

Nonetheless, while there is mention in *Better Births* of vulnerable women “such as drug and alcohol users, sex workers and homeless people”, there is little exploration of the experiences of disadvantaged mothers or of how services can meet their specific needs.

Despite growing evidence that women facing multiple disadvantage experience poorer outcomes and are more poorly served, the concept of multiple disadvantage remains under-explored in maternal health research and policy and there is no national data to show the prevalence of women who face multiple disadvantage during the perinatal period. The most recent National Institute of Health and Care Excellence (NICE) guidance on supporting pregnant women with “complex social factors” was published in 2010 and does not refer to multiple needs<sup>3</sup>.

The perinatal period is one of great opportunity when, with the right support, families can make changes in their lives in order to improve outcomes for themselves and their babies. In this context, this peer research report is both significant and timely. The women interviewed for this research had experienced multiple disadvantages. Some experienced drug and alcohol addiction, mental health issues and domestic abuse. This often lead to homelessness, financial hardship and involvement in the criminal justice system. Many of the women we spoke to were survivors of extreme trauma, such as childhood sexual abuse, sexual violence and neglect. Despite this, the majority of the women were doing well. They were moving on, and their children were well cared for – the result of their own hard work, good multi-agency working, the care of specialist midwives and the impact of the work of the voluntary and community sector.

This report is an opportunity for 34 women to tell their stories; women whose voices are rarely heard by mainstream services. A theme running through the research is that women facing multiple disadvantage wanted more opportunities to be heard. Many experienced extremely good care but some women felt isolated, judged, afraid and embarrassed. They wanted to be asked how things were at home and told us that they wanted more choices and greater support. Cumulatively, their insights go beyond their own stories to offer direction to those who commission and deliver services.

Significantly this research was led by women with experience of multiple disadvantages – peer researchers. Unlike the majority of research in this field, peer research addresses power imbalances and questions current epistemological norms. This report demonstrates how the expertise of researchers with experience of multiple disadvantage offers unique, deep insight. During a period of transformation in maternity services this evidence is important in informing services trying to meet the needs of the most marginalised women and their babies. As this report underlines, co-production with women who face multiple disadvantages should be an important part of ensuring the vision *Better Births* sets out is realised for all women.

# Background and policy context

## Health inequalities, complex social factors and multiple disadvantage

*“I’ve been in the criminal justice system. I’ve been in domestic violence. I’m going to be becoming homeless soon.”*

We know that there are significant health inequalities associated with certain demographic populations, and others with what maternity services term ‘complex social factors’. These are expressed through poorer outcomes: mothers living in the most deprived areas are around five times more likely to die than those in the least deprived areas and babies born to mothers living in the most deprived areas are more likely to be stillborn or die in the first week of life than those in the least deprived areas. Babies are also more likely to have a low birthweight and to be born prematurely if their mothers are: under 20; from lower socio-economic groups; some Black, Asian and Minority Ethnic (BAME) groups; or born in Africa or South Asia<sup>4</sup>. Poor maternal mental health is associated with poverty, single parent status, and youth.<sup>5</sup>

Women in these groups also experience poorer access to maternity care. Mothers who have a low socio-economic status, belong to a BAME group, have little education or are very young, more frequently come to maternity services later and do not make all of their appointments.<sup>6</sup> Certain groups, such as those seeking asylum, facing homelessness and using substances, might not present to maternity services for fear of judgement or having their children taken away, or they may just be unaware what support is on offer.<sup>7</sup>

Definitions of disadvantage vary between services and systems. East London Local Maternity System lists “complex social factors” as: young (under 20), homeless, recent migrant in the last 12 months, refugee or asylum seeker, learning disability, domestic abuse, safeguarding or unable to speak or understand English.<sup>8</sup> Current NICE guidance identifies pregnant women as having complex social factors if they present experiencing alcohol or drug misuse, recent migrant or asylum seeker status, difficulty reading or speaking English, aged under 20 and domestic abuse.<sup>9</sup> There is debate about whether the factors listed above are comprehensive enough. In a recent surveillance exercise, experts consulted by NICE on updating its 2010 *Guidance on pregnancy with complex social factors*<sup>10</sup> suggested adding, amongst others:

- Mental health and personality disorders
- No recourse to public funds
- Female Genital Mutilation
- Trafficked women

Birth Companions’ extensive and longstanding work with perinatal women facing severe disadvantage, and Revolving Doors’ work with people facing multiple disadvantages, suggests this list should be more comprehensive, covering current or historical factors which can impact adversely on women’s experiences during the perinatal period, including: existing mental health issues, criminal justice involvement, significant financial needs, physical disability, current involvement with social services and a history of being looked-after.

There is little data available on the co-occurrence of multiple disadvantages or complex social factors during the perinatal period. However, we do know that pregnant women with multiple needs are less likely to access maternity care, or will receive less of it; have poorer maternal and infant outcomes; and are more likely to experience perinatal mental health problems<sup>11</sup>. Recent research identifies that in the general population, women who experience some complex social factors are more likely to experience others. For example, women with experience of severe physical and sexual violence are far more likely to have physical and mental ill health, and eight times more likely to be drug dependent than women with little experience of violence and abuse<sup>12</sup>.

It is this group – women experiencing multiple complex health and social factors – who are the focus of this study. While maternity services have guidance on working with women with individual presenting factors there is no current framework for understanding and meeting the needs of women who experience multiple disadvantages.

For the purposes of this research we combined three sets of factors from East London Local Maternity System, NICE and Birth Companions/Revolving Doors to determine the scope of this research.

### Factors determining the scope of this research

- Domestic violence or abuse
- Substance misuse
- Mental health issues
- Criminal justice involvement
- Homeless
- Young (under 20)
- Physical disability
- Learning disability
- Significant financial need
- Recent migrant or refugee
- Does not speak/understand English
- Social services involvement

Women were deemed to face multiple complex factors if they experienced three or more of the factors listed above at the same time.

### National context

In February 2016, the National Maternity Review *Better Births* set out the Five Year Forward View for NHS maternity services in England. NHS England established a Maternity Transformation Board to oversee the delivery of the policy and recommendations. This board recognised the vital role of local leadership and action in making sure its vision is achieved. It formed Local Maternity Systems that bring together commissioners, providers and service users to plan and deliver maternity services.

Putting into practice the vision set out by *Better Births* will support the Secretary of State's ambition to halve the number of stillbirths, neonatal and maternal deaths and brain injuries by 2030. The shared goals that permeate all work streams of the Five Year Forward view are: family-friendly; kind; professional; personalised and safe.

NHS England states: *"to achieve the cultural shift that is required to deliver the vision and objectives of Better Births, Local Maternity Systems will need to engage in strong and effective co-production with women and their families in the transformation of maternity services."* In 2017, NHS England published *Implementing Better Births: a resource pack for Local Maternity Systems* setting out in greater detail how the vision would be achieved in local areas. This guidance states that *"vulnerable women will need extra support to ensure they receive high quality personalised care empowered to make choices."*

### **North-east London context**

This research explores the maternity experiences of women facing multiple disadvantages in two north-east London boroughs – Hackney and Barking and Dagenham. The work was planned in collaboration with the East London Local Maternity System (ELLMS), which has governance arrangements aligned to the East London Health and Care Partnership. This partnership comprises seven Clinical Commissioning Groups (CCG) with a combined population of around 1.9 million people. The area is characterised by socio-economic, ethnic, linguistic and health diversity. It is also one of the most deprived areas in the capital: five of the CCGs are the most deprived in London.

In 2017 16% of women in the East London Local Maternity System presented with one or more complex social factors.<sup>13</sup> North-east London is rapidly growing, with predictions of an 18% increase in the population in the next 15 years, and 1,200 more births expected over the next five. The number of women experiencing complex social problems could continue to increase to 25% in 2018, and 40% by 2021.

# Methodology

## Peer research

This is a participatory piece of research located within a community development perspective. This means that people who are normally the subjects of research were directly involved in designing, implementing and analysing this study. A secondary aim was to develop the peer researchers personally in the process.

Participatory research, as an approach, was originally developed in the 1970s and 1980s as an alternative to large-scale survey studies which were perceived to give insufficient attention to people's local knowledge.<sup>14</sup>

One of the unique features of the research is emphasis on the use of peer researchers. They are already in the world of those being researched and share a common language and experiences. This encourages research participants to open up to peer researchers in a way that can be difficult in traditional research due to power dynamics. We recognise that research participants often prefer to speak to someone who is perceived as credible, and their perception of personal experience is key.<sup>15</sup> Aligned with this is a general mistrust that those with multiple disadvantages have towards perceived authority figures and educational establishments,<sup>16</sup> including university researchers. Implicit in the work of peer researchers is the understanding that they will reveal information about their own experiences as a part of the process. One of the peer researchers commented on this when reflecting on the project:

*“It was amazing how they felt comfortable enough to share their amazing stories with us about their experience before and after giving birth. I noticed that one woman seemed quite vulnerable. Once I told her about myself, she became more relaxed.”*

In total, eleven peer researchers participated in this project. Peers were defined as women who had experienced multiple disadvantages. They were recruited from Revolving Doors' and Birth Companions' networks. Women received Revolving Doors' OCN-accredited training in peer research. They were also provided with other training, in human rights in childbirth for example, and given a personal development plan, as well as regular support from an involvement manager. Since completing the project, all peer researchers who wanted to do so have gone on to paid peer research focusing on maternity services in a different London local maternity system. Others have moved on to new opportunities. All of the peer researchers who took part were offered options for progression and other opportunities at Revolving Doors or Birth Companions.

## Ethics, participant access and inclusion criteria

The women who were interviewed had experienced some aspect of maternity care in the boroughs of Barking and Dagenham or Hackney, had been pregnant or given birth in the last five years and had experienced three or more of the multiple disadvantages listed in the introduction.

Local services in Barking and Dagenham and Hackney were mapped and contacted by Revolving Doors' staff or peer researchers. Information sent to services explained the scope of the project and asked for interviews with women who had experienced multiple disadvantages. Peer researchers visited

several services in advance to explain the project in person and outline the aim of the work, and benefits of a peer research approach.

In total, there were 34 participants:

- 20 had experienced care in Barking and Dagenham
- 14 had experienced care in Hackney<sup>17</sup>

The women were accessed through different routes. The majority of women were recruited through local statutory and Voluntary Community Sector (VCS) support services (see table one below). A smaller number of women were accessed through contacts of Birth Companions and the peer researchers.

**Table one**

Hackney services	Barking and Dagenham services	Peer routes
<p><b>Pause (3 women)</b> Pause Hackney works with women in the borough who have experienced, or are at risk of, repeat removals of children from their care. Through an intense programme of support, the organisation aims to break this cycle and give women the opportunity to create a more positive future.</p> <p><b>Playbus (3 women)</b> Hackney Playbus provides play, learning and support to socially excluded families in east London, to encourage children’s early years development, and strengthen families and communities.</p> <p><b>Westminster Drug Project (WDP) The Orbit Centre (3 women)</b> The Orbit is an inclusive drug and alcohol service for expectant mothers, and anyone caring for a child under 5 years old. They have specialist substance misuse midwives, counsellors and support workers.</p> <p><b>Linden Children’s Centre (1 woman)</b> The centre is for families with children under five living in Hackney. It offers free stay and play sessions, health services and family support.</p>	<p><b>Excel Women’s Centre (9 women)</b> The Excel Centre helps vulnerable women and their families by offering a range of services. These include housing advice, health and wellbeing, education and training, work club, social and networking group and a mental health support group.</p> <p><b>Shpresa, Barking and Dagenham (10 women)</b> Shpresa is a user-led organisation that supports Albanian-speaking women in the UK with education, health and wellbeing.</p>	<p><b>Birth Companions (1 woman)</b> Birth Companions supports women experiencing severe disadvantage during pregnancy, birth and early parenting.</p> <p><b>Peer researchers’ contacts (3 women)</b></p> <p><b>Choices Islington (1 woman)</b> A service for women with unplanned pregnancies, post-abortion counselling, child separation, and practical help with baby clothes and equipment. One woman was interviewed through this service who had previously received care in Hackney.</p>

Women were recruited to take part in the research in two ways. Some recruitment happened at services, with peer researchers meeting women and inviting them to participate at a later date, arranging an interview time. In other cases, service staff used information provided by us to introduce the project to the women they worked with. Then staff arranged a time for the interview with women who wanted to take part. Interviews took place wherever it was convenient and safe for the women involved.

Informed consent was sought from all participants through an information sheet, discussions in the recruitment process and the completion of a written consent form outlining the purpose of the research, areas for discussion and permission was requested to record the interview. Women were able to end the interview at any time, take breaks and ask questions at any point. All women were debriefed at the end of their interview, ensuring that participants were not distressed and had support available.

Women completed an optional demographic form. Of the women we spoke to who completed the demographic form fully: seven were Black British, six were dual or multiple heritage, four were Black African or Caribbean, four were White British, one was Asian and seven identified as Albanian on the form. Five women needed to have interpreters. The majority of participants (n = 23) were between 25-39 and all were primary carers for their children.

Women were also asked to review a list of services they had accessed and/ or needs they felt applied to them. A small number of women chose not to complete the section of the form which asked them to tick whether or not they had experienced some needs. In these cases, it was judged from the interview content and the services they accessed whether the women had experienced multiple disadvantage.

The average number of disadvantages identified through the demographic form was 3.5. Within our sample the following issues were identified:

- More than half had experienced mental health issues
- More than half had experienced homelessness and/or housing difficulties
- Half had experienced domestic violence and abuse
- Half had experienced significant financial need
- A quarter had difficulties speaking or understanding English
- A quarter had experienced social services involvement
- Three women had a learning disability

## Methods

In total, there were 26 semi-structured interviews and one focus group with eight people. Interviews were face to face and were co-conducted by peer researchers, with a member of Revolving Doors involvement team as a support, or secondary, interviewer. The topic guide was structured to understand women's journeys from antenatal, birth and postnatal care, and how this was experienced. Interviews explored what information women had received and how they felt about: various stages of their perinatal journey, maternity professionals, what could have been improved and their choices and support.

Initial research was conducted mainly in Barking and Dagenham between September and December 2017. Further data collection took place in Hackney between March and July 2018. The first phase in Barking and Dagenham had been successful, in particular, in reaching women for whom English was not their first language, were recent migrants and from a BAME background. The majority had experienced significant, concurrent or recent trauma<sup>18</sup>, including the experience of trafficking and violence leading to women's participation in the asylum-seeking process.

It was agreed that the research would benefit from speaking to more women with substance misuse problems and contact with the criminal justice system. The next phase of recruitment in Hackney included purposeful sampling and proactive contact with services such as Pause to identify women with these experiences.

Interviews were recorded and transcribed (with the exception of one woman who did not wish to be recorded and so notes were taken). Thematic analysis was undertaken with peer researchers and Revolving Doors staff at mid-way point and at the end of data collection.



More than half had experienced mental health issues



Half had experienced domestic violence and abuse



More than half had experienced homelessness and/or housing difficulties



Half had experienced significant financial need



A quarter had difficulties speaking or understanding English



A quarter had experienced social services involvement



Three women had a learning disability

## Findings

Research findings are divided into five sections, which are structured around the aims of the Better Births report most relevant to the focus of this study. This was agreed with peer researchers and commissioners at the data analysis stage to be the most useful structure to present the findings. The aims deemed most relevant were the first five aims within Better Births. Further aims related to commissioning structures and payments for providers were not relevant. Any findings that do not fit within the Better Births priorities are grouped in a final section entitled Other key findings.

### Better Births Aim 1

Personalised care, centred on the woman, her baby and her family, based around their needs and their decisions, where they have genuine choice, informed by unbiased information.

## I. Women feared and distrusted services

Many of the women we interviewed feared and distrusted services, including maternity services. They often felt unable, or scared, to make their choices clear to health professionals. This had an impact on how they engaged with services, and their care.

Women interviewed in this research were not always able to make their needs known. Indeed, when asked what would have improved her experience across maternity care, one woman said simply “speaking out”.

This fear of services manifested in different ways and for different reasons, but was often related to fear of having their baby removed or to a fear that if they disclose a problem (for example a mental health need) they would be subject to high levels of scrutiny rather than support.

### Fear of baby removal

Several women feared they would be separated from their baby. “You get scared they are going to take your baby” said one woman.

Although the role of social services was most frequently discussed, fear of services in general and being scrutinised had an impact on how women viewed maternity services. This affected women’s ability to articulate their feelings, choices or concerns during their care by maternity services. On being asked if she had any concerns about engaging with maternity services, one woman said: “...I still don’t want to like put a foot wrong or anything like that...I am afraid even to talk to them, or tell them how I feel, or if I have got a complaint or something.”

Many of the women discussed their care in a way that implied a strong power imbalance. Regarding a decision that baby was not coming home with her, one mother said: “It’s with authoritative people you know. You know it’s procedure that they have to follow”.

### Fear of being over-scrutinised

Women said they did not engage earlier with maternity care because they feared social services would get involved in their case. There was a perception

that this could happen for a number of reasons. For example, women said this could be due to their refugee status, substance misuse, or being found to have postnatal depression.

*"I wondered about the extra support. Then she misunderstand me, she called in the social worker. She opened a case for me."*

*"The fact you're asking for help, sometimes you are labelled, fear of, that you can't cope...[.]... You'll be judged. You're feeling like you can't look after your baby."*

*"It was nice, I felt like I was at home with baby, rather than at the hospital with everyone watching what you do, how you are and what you say."*

## 2. Many women felt excluded from decision-making

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Women often found the system unclear and non-transparent. One woman was allocated a midwife from the drug and alcohol team and attended an antenatal appointment with her, but she was not told about the specialist nature of this midwife until a subsequent child protection meeting:

*"It just felt quite covert and I wished they'd be more honest with me. Like, 'I'm from the drugs and alcohol team. Look, your GP told us!'"*

Another woman described not being included in discussions with professionals:

*"There was somebody called MAT. I know it stands for Multi Agency Team. Like then they were discussing my needs..."*

Another said: *"My choices? It was all negative in that sort of experience. It was all, I didn't feel like my choices were considered. Just because, like, you know, just because I had a drug problem, you know."*

Women valued understanding the processes affecting their choices and being included in decision-making. One pregnant woman who hoped to keep her baby and regain custody of her toddler, was asked how involved she felt in her care plan:

*"I actually do feel rather involved. They asked me what I wanted to do. I've told them, and we are working towards it, so I am actually really happy with that. I feel really confident going into next year as well."*

Another woman said: *"My voice was heard, you know, they took my issues to heart."*

It was clear from the interviews that women facing multiple disadvantages were often distrustful of services, but there was potential to mitigate this by supporting women to understand choices and processes better and include them fully in decision-making.

## 3. Women wanted to be asked about their situations so that their specific needs were understood

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In contrast to the fears outlined above, some women felt professionals should have asked them more consistently and in more detail about their home situations in order to understand better the range of difficulties they faced and the help they might need. In particular, they wanted to be asked about domestic violence and abuse, and the wider context of drug use in the home

or family and they recommended professionals should not assume they were fine if they looked well.

*"Nobody actually asked, 'Is anyone in the house using?' If anyone had actually said, 'Is everything alright at home?' You know, just a question like that, I would probably say, 'No, it's been a bit hard, you know.'"*

Several women had similar reflections:

*"I was going through this domestic violence, but when I went to the hospital for my, what's it called, my scans and stuff. It would have been nice if the midwives had asked me, 'is there anything you need to talk about?...[. . .]...If the midwives take time to just, try and find out a bit about your life. A bit about your history. You know? Because some women, they look like they're the happiest people in the world, but actually, you don't know what they're going through, you know?"*

Another woman with mental health problems said:

*"...there wasn't like a deeper conversation, are you sure or is there anything else we can do to help?...you're sorted and that is it. ...[. . .]...Even if I would have said I'm not ready right now, at least to be offered".*

She described how this offer could have been presented to her to help her engage with services:

*"...even if it was someone who didn't have the title Mental Health, or just kind of like somebody to talk to. 'Cos I do think the term Mental Health can scare off quite a lot of people. 'Cos that's what happened to me at the beginning. I didn't want to be deemed as having depression or anything like that".*

One woman with mental health problems described the impact of her partner's mental health problems on her own wellbeing during pregnancy. Later in her pregnancy the couple were able to tell the midwife about the mental health challenges, and that he was suicidal. The midwife referred them to a project called Bump Buddies where they are accessing good support.

Women felt that maternity services had often made assumptions, for example, that women who dress smartly and speak well do not have any problems. A woman who experienced domestic abuse, coercion and drug use during pregnancy, said:

*"I'm quite well-spoken and you know I'm not so used to social services or any of those services so I guess I'm not the type of person I think that people...Especially in Hackney, you know there are so many other problems".*

Another woman had experienced physical and sexual violence at home, had her passport removed by her in-laws, and was prevented from leaving the house to seek help. She said: *"Actually, ask every woman that walks in, 'Do you need any help?'"*

#### 4. Women engaged later with maternity care

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The ability of maternity services to respond quickly depended, to some degree, on how they engaged with women early on in pregnancy.

Our research confirmed current evidence that women with multiple disadvantages engage less with antenatal care overall, and that they do so later on in pregnancy.<sup>19</sup> The women we spoke to outlined some of the challenges they faced and the reasons for later engagement.

Some were not registered with a GP and thought they had to do this in order to tell services they were pregnant. Others engaged with services late because of multiple reasons, including drug use, domestic abuse, fear and distrust of services and practical challenges.

One woman was “...*was smoking crack and taking heroin every day*” but still wanted to access help when she realised she was pregnant.

*“I realised quite early on, I just knew, but I was in denial about it for ages. Because I was taking drugs I didn’t want to like think about it too much. I just hoped it would go away. So then I did a pregnancy [test] at home...I didn’t even have a GP at the time. I had to go and register and everything”.*

Another woman had her booking in appointment at 12 weeks, “*very late I guess cos a lot of people have it earlier I believe*” because she had been considering a termination. She had gone to an appointment for a termination and “*just couldn’t do it, it was a very uncomfortable ordeal. Especially as I’d already been through it once before*”.

Another woman had engaged late with services because she had experienced pressure from her partner to seek a termination.

Yet another woman described suspecting that she was pregnant at eight to nine weeks and needing to hide it from her partner; finding a time to do the pregnancy test when he was busy. “*I couldn’t go anywhere without him and that was the only time I could get out,*” she said. The woman was able to leave her abusive partner, report him to the police and move into a refuge.

These issues all contributed to late engagement with maternity services and point to some of the challenges in supporting women early on. However, all the women we spoke to did eventually engage with services, creating opportunities for support. This reinforces the finding that as soon as a woman facing multiple disadvantages asks for help, support should start as quickly as possible to achieve the best outcomes.

Finally, late access to maternity care had an impact on women’s preparations for birth. This was compounded by the high number of women in our sample who gave birth earlier than their due date; consistent with the evidence base that vulnerable women are more likely to give birth earlier.<sup>20</sup> At least two women described writing their birth plan within a week of giving birth. One described herself as “*under-prepared*”. Sometimes, leaving the birth plan to the very end of pregnancy related to lack of knowledge: “*It wasn’t like she [the midwife] didn’t care, it was probably just me not really knowing what to write.*”

## 5. Women reported breaches of confidentiality

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Some women reported that breaches of confidentiality had taken place during their care which had caused emotional harm.

One woman described her experience staying on a shared ward for two weeks post-birth. She was not given a private room as she had been judged to be “high risk”. Conversations with key professionals about her situation (drug use and potentially having her baby removed) were held on the ward with only the curtain pulled round, offering no confidentiality.

She described this as shaming, isolating her from the other women on the ward, whose attitude towards her changed as they heard her situation: “*it was embarrassing, having loads of appointments, having social services and having just a curtain so everyone can hear*”. The isolation from other women was particularly upsetting at a time when she already felt alone.

Other women said that their confidential information had been passed on to other professionals without their knowledge or explicit consent, and that this had scared or upset them.

## 6. A compassionate and non-judgemental approach had a significant impact on women's satisfaction

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A key theme from the women interviewed was the attitudes of individual professionals. Compassion and a non-judgemental approach made a tangible difference to women; indeed, kindness (or lack of it) could shape people's experiences profoundly.

One woman described how her birth was difficult and not what she had planned. She had been induced and the baby had passed meconium, leading to a forceps delivery which meant she had not been able to have immediate skin to skin contact with the baby. Despite this, she went on to describe her birth experience, at the Homerton University Hospital, in the following way:

*"I thought it was wonderful. Like from the second, even the lady who when I was admitted that was just down on the reception, she actually came to say congratulations. I thought like, I had the best, I was so happy from beginning to end".*

However, the same woman then described being moved onto the post-natal ward for two nights:

*"I was just really shocked about how little the staff cared. It felt very different to how it was at the birth place. . .[.]. I felt quite wired and weird and scared. I guess that's how I felt a bit you know, please just be nice to me. I've just given birth."*

The women we spoke to were highly attuned to being treated "differently" to other women. One described how her midwife, who had allowed her to breastfeed because her drug use was "borderline", had said, "I was lenient with you when it came to breastfeeding". The woman found the word "lenient" to be patronising and upsetting.

One woman described her first appointment with her midwife: "She hardly looked at me, she was very cold." The woman went on to say how she had wanted to talk about the pregnancy and her expectations but, "I didn't end up asking anything because I felt just a bit stupid". She later transferred to another midwife who she liked.

Others reported very positive experiences:

*"The doctor was really un-judgemental, the consultant".* This consultant gave the woman a photo of the baby which she prized.

Another woman simply said of the Homerton University Hospital: "they really treat me well"

One woman, whose baby was removed into care at eight weeks, said:

*"To me the only proper nice experience that is basically when I was in with the midwives and I had the baby if you get what I mean in the special baby care unit because I was able to bond with her, hold her as much as I want, the midwives was really helpful and caring and in that whole sort of period that was the best experience."*

In terms of solutions, women understood and acknowledged the pressures on midwives and other health professionals. One offered the suggestion, "maybe like some training, or maybe some midwives who've had similar experiences".

## Better Births Aim 2

Continuity of carer, to ensure safe care based on a relationship of mutual trust and respect in line with the woman's decisions.

### 7. Continuity of carer was highly valued

One of the key themes emerging from our interviews was how much women facing multiple disadvantage valued having continuity of carer and how far this went towards addressing some of the issues above, including fear and distrust of services.

All women were asked what they would like to see changed about perinatal services. In response to this open-ended question, approximately half spoke about better levels of consistency. Many related this to trust and reducing fear:

*"Have one person to see you so you don't have to keep answering the same questions over again and you can get some trust."*

*"To have the same person with you throughout if possible don't be frightened to change if you are not happy."*

Women preferred a model where they had the same midwife during antenatal, birth and postnatal stages. One woman, who had a traumatic caesarean birth, followed by a blood transfusion, said: *"looking back on it now, I think I'd like it if my own midwife was there"*.

One woman, who had previously experienced four miscarriages, said:

*"I met a midwife soon after the first bleeding I think but she wasn't to be my midwife for the rest of the term...[.]. speaking to someone initially and then finding out that she's not actually going to be my midwife."*

Another woman, describing her relationship with a social worker during pregnancy, highlighted why continuity of carer matters: *"it took me at least three times of me seeing her, for me to really get it out because it was like, I don't want anyone else laughing at me."*

Even for women who did not have an entirely positive relationship with their midwife, continuity of carer was still appreciated:

*"It felt like every time [in another London borough] I saw different midwife. Here I had the same midwife every time. She was a bit judgemental but anyway at least I built some rapport."*

Others spoke of their experiences in a way that accepted that inconsistency was part of their care. Because they did not know what was expected, they were unsure whether this was standard practice. Several women spoke about either their own, or their peers' experiences of seeing multiple care providers in the perinatal period, and being unclear who their appointment was with or when they were:

*"When I went home, I saw three different midwives and one health visitor, but all my appointments were good when I eventually got a date."*

*"I think everything is okay but I don't know, maybe here is different from Albania because in Albania we have a doctor, I call my doctor in every moment... but when I go in hospital every appointment I see different people...and I don't know who is my doctor"*.

For women who saw several midwives lack of continuity of care could be mitigated by a consistently caring approach: *"I had a fourth one that was there for labour, but they were all fantastic."*

### Better Births Aim 3

Safer care, with professionals working together across boundaries to ensure rapid referral, and access to the right care in the right place.

## 8. An early response to problems and swift referrals maximised chances to improve outcomes

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Once time had been taken to ask about and understand their needs, women wanted rapid help to ensure they could start to tackle problems as early as possible. It was important for women that services responded to these requests for help quickly, within what was for many, a short period of opportunity. It was clear from the experiences women related that accessing help and addressing problems as early as possible could have a profound effect on the outcomes of families, particularly if there was uncertainty about whether they would retain custody of babies after birth.

Several of the women who moved to Hackney during pregnancy noted more rapid help in the borough than in the one they had moved from. One woman reported taking drugs every day and shoplifting regularly to fund the habit while she lived in another London borough. Despite asking for help, she did not receive it rapidly enough and described the drug service there as “terrible”. Once she moved her experience was very different:

*“...when we moved to Hackney then that’s when it started moving. But I was way further along, I was six months pregnant at this point. ....They [Hackney] were just so good, like straight away, when I missed an appointment they saw me the next day. And they gave me a script like within a week I was on a script”.*

This woman was able to “get clean” when she was eight months pregnant and had custody of her baby. It was clear from her interview that any further delay would have had an impact on her ability to keep custody of her child.

Another woman described the support she received when she moved to Hackney at 12 weeks pregnant to live in a refuge: *“we started working on things straight away and yeah it was really good. I got introduced to my social worker within like three weeks”.*

## 9. Specialist midwives make a positive difference

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Specialist midwives were key to good outcomes for the women we spoke to. The women who accessed them were positive about the difference the support made.

A woman who had experience of domestic abuse, criminal justice contact and was at risk of homelessness, said: *“I also had a midwife who was specially there for people who’ve lived through domestic violence, and she basically referred me to [specialist domestic violence] ante-natal classes.”*

Another woman, who indicated she had been supported by a specialist mental health midwife, felt this meant she could manage better. Several home visits from the midwife before the birth, because of her mental health needs, were appreciated. She was currently supported by a multi-agency team but said that they were planning to close her case. *“I managed. And I’m still managing,”* she said.

#### Better Births Aim 4

Better postnatal and perinatal mental health care, to address the historic underfunding and provision in these two vital areas, which can have a significant impact on the life chances and wellbeing of the woman, baby and family.

**This priority was highly relevant for the women in this research, as the majority had experienced mental health problems. Importantly, women did not experience this in isolation. They had to cope with mental health problems in addition to, and often concurrent with, other issues such as domestic violence, severe financial hardship or substance use.**

### 10. Specialist mental health services were offered very late in pregnancy

The women we spoke to who accessed specialist mental health services did so late in their pregnancy. Some received help only a few weeks, or even days, before the birth. There was a clear need to access services earlier and for them to be more co-ordinated. However, once accessed, these services made a tangible difference to women.

A young woman had previously received mental health care when she was 15 so was known to services:

*“it took me a while to get a referral to the perinatal mental health team but I did finally get referred which I found very helpful. But at that point I was really late into my pregnancy and I’d already dealt with a lot of it by myself...not very well but I found ways to cope with it.”*

Another referral relied on the woman calling and accessing help proactively.

*“I wasn’t really offered much support apart from when I went to my first booking in appointment – I was given the number for the perinatal mental health team and that was about it. It took me a while before I admitted that ok I wanted to speak to somebody and then to get the ball rolling.”*

She received her first mental health appointment the week her baby arrived, as he was early.

Another woman felt she was doing well with her mental health during pregnancy, but found out about her partner’s extensive covert drug use, and his financial abuse of her shortly after the birth: *“It kind of came out when my son was six weeks.”*

She went on to talk about her partner’s hidden debts, use of prostitutes and financial coercion: *“I think maybe I had known it when I was pregnant, but I subconsciously kind of ignored it”*. The woman eventually accessed services when her baby was seven months old. This meant she did not receive any help for the domestic abuse and financial control in the first seven months of her baby’s life.

She was accessing support regularly at the Orbit Centre which she had found by searching online herself after a period when *“I really spiralled down like mentally”*. She found the service particularly accessible because she could bring her baby with her to attend therapy sessions and the staff were not judgemental about her family situation.

When asked what interventions might have helped earlier or could have been offered by health professionals, she said:

*"...to not take everything at face value I guess it's very hard to kind of explain that because if I'm smiling and saying that things are fine it's not like someone's going to say, no, it's not fine, but I guess maybe the questions sometimes. They were focussing on, they were quite robotic you know, they focus on if you smoke, you know the kind of easy things to do like are you using drugs, like no, I'm not."*

From our interviews, it was clear that women were sometimes accessing mental health support through their own initiative, and that opportunities are missed in the antenatal period to identify and refer women for support earlier.

## **II. Women valued continued support in the post-natal period**

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Many of the women described feeling under-prepared for the first few weeks following birth. This experience may be common for many women giving birth, but women with multiple disadvantages experience higher levels of social isolation and are likely to need greater levels of support to manage the care of their baby and the other challenges in their life.

Many of the women who had recently entered the country as asylum seekers, and had difficulties understanding or speaking English, implied that they were socially isolated and needed additional support:

*"I don't have my family and I can't have that support. But at least I'll have my daughter."*

There were particular problems regarding lack of aftercare plans, including for women with mental health problems as many had very little support from families or friends.

One woman, with depression and severe financial hardship, said: *"I was hopeless, because in hospital they do everything for you, but now I had to go and face everything by myself"*. The same woman was using a foodbank and had multi-agency team involvement.

One woman, who was pregnant and staying in a refuge, said: *"I really don't want the support to stop after the child is born, and I don't want to leave here in one or two months either."*

Women described a focus on their physical health rather than their wider needs post birth.

*"I think they were more concerned about my physical wellbeing rather than anything else. That's how it felt to me at the time...but if you're not okay in your head then, you know..."*

This woman, who had mental health needs, went on to describe being discharged from hospital: *"the person in charge when we left the hospital just gave us like 'you need to read this. This is our telephone number if you have any problems'. Kind of. You know? It wasn't like really talking anything through."*

She was eventually referred to child and adolescent mental health services (CAMHS). Once a midwife knew the situation she got some extra support, and it was clear that this additional support from midwives was key:

*"...when she found out that my husband being depressed, so, we had 28 days' aftercare rather than the standard two weeks. Which was good because I think we really needed it at that time"*.

Another woman was still waiting for help:

*"I am waiting for a counsellor now... they told me its gonna take long time and I don't know, I am taking medication but I don't want to take you know, every time medication... it's going to help me sleep better but next day morning, it's still the same you know."*

Women generally said that offers of support should be made face to face, where possible. After birth, they were not able to digest all the relevant information in written form to seek help.

*"...they gave lots of paperwork which, to be honest, I don't even think I've read of it to this day."*

## 12. Many women experienced co-occurring or recent trauma and high levels of domestic violence

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Trauma was understood to be significant challenges causing deep emotional distress experienced before or during the perinatal period. Many of the women we spoke to had experienced trauma immediately before, during or after the pregnancy and birth. The majority of the women we spoke to in Hackney had experienced domestic violence and abuse. *"Everything became very toxic and difficult,"* said one.

Many women spoke less about trauma related to pregnancy and birth than trauma in other areas of their lives, such as domestic abuse. One woman explained that *"...for us, the pregnancy was the most easy part ... compared to other things that happened to me."* However, women who had had their babies removed described this experience as a profound trauma.

All the women we spoke to accessed maternity services, despite fears of having their baby taken away, lack of confidentiality and concerns for their safety. This indicates there is significant opportunity in the perinatal period to offer women help with the issues they face in relation to trauma (past or current) and other complex social needs – if these are identified. Specialist midwives, alongside maternity services, could support women with these highly complex needs.

### Better Births Aim 5

Multi-professional working, breaking down barriers between midwives, obstetricians and other professionals to deliver safe and personalised care for women and their babies.

## 13. Women reinforced the need for agencies and professionals to work together

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Women with multiple disadvantages often need multi-agency support and the effectiveness of their joint working made a difference to the experiences of the women we spoke to. One woman was pleased that her midwife and support worker were working together: *"I know them two work together. I think it's good when the services all work together and share that information as well."*

For several women, delays caused by poor information sharing caused disruption and frustration.

One woman reported that a decision needed to be made regarding whether or not she was allowed to breastfeed due to her recent drug use, but her baby was born on a Saturday night and the midwife was not available until Monday morning. This meant that she could not start breastfeeding until over 24 hours after birth. She attributes stopping breastfeeding at six weeks to this hiatus:

*"When I gave birth, I didn't get on that well with the midwife. She had said I*

*couldn't breastfeed unless it had been a certain period I hadn't used, and I think it was on the cusp of that. And they didn't want to let me breastfeed, and so that put me behind in breastfeeding."*

She explained that information had not been passed on to another health professional who could have made the decision while her dedicated midwife was not available.

#### **14. The role of voluntary and community services was important**

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The involvement of the voluntary and community sector improved outcomes and was highly valued by the women we spoke to. However, our research found that referrals to voluntary and community services from maternity services were inconsistent; successful referrals relied on individual professionals knowing what was available and identifying the need and this did not always happen.

Women who accessed local voluntary and community services praised them highly and said they made a big difference:

*"The charities seem to understand more than the professionals. They can refer me to other services if I need help."*

*"Orbit is the only place I go to so that's mainly just like...to get a bit of a break and to have my son having someone to play with but also to meet women that kind of know what's going on really."*

Women said that staff were very skilled and had a non-judgemental, positive approach. They were able to discuss their family situation and get help, bringing their baby with them. One woman had tried another "generic" drug service and found it inappropriate for new mothers.

On asking for support about "learning to be a mum" another woman was referred to Birth Companions by a specialist domestic abuse midwife:

*"So, she put me in really good ones. With Birth Companions. And I feel like I know everything I need to know about being a mum really...[...]. And, to be honest, like, although I've been through domestic violence and everything, like, these classes, just attending them, just having a bit of that social life, you know, being able to actually learn, you know, be prepared mentally has actually mentally helped me. It's like, you know, I don't know what I would have done being a pregnant mum being on my own. You know. This is mentally, I think is the main reason why I haven't fallen into any depression or anything."*

For many women centres run by the voluntary and community sector provide services that are non-threatening, addressing their experiences of trauma and feelings of isolation:

*"...it's a friendly space and it's time to have a baby, should be fun."*

*"You know, all the women that come here, I mean this is their second home. I mean, you can come any time, make yourself a drink."*

Several women were not offered referrals to voluntary sector services at their midwife appointments. *"I didn't go to anything during my pregnancy,"* said one. This appeared to be a missed opportunity.

Yet it was clear that there were several specialist services available in Hackney for women with multiple disadvantages that midwives and other health professionals could refer women to who needed this help.

Another pregnant woman experienced domestic violence, was a recovering alcoholic and had had her previous children taken into care. She was positive about the care from voluntary sector services in Hackney:

*"...the last borough I was in...it didn't help me at all and I ended up getting worse. But being here is really good support and these sort of groups I come to... [...]...it's a nice thing you feel welcome".*

## Other key findings

### 15. Women at risk of having their baby removed wanted better preparation and better post-separation support

Women at risk of having their baby removed into care expressed a desire for honest information and practical help. Many needed preparation for what was to come and said they would like bereavement counselling to be offered in pregnancy. One woman asked for "a grief counsellor" earlier in her journey, similar to the support she was now getting through Pause Hackney.

Another woman knew from very early on in pregnancy that her baby would be taken into care but did not receive support around this from maternity services during pregnancy or at birth.

*"To me it was all just about taking the baby you know, really. They never really asked, really, you know, me being sad..."*

Her needs are now being met by a support worker:

*"...that's why I'm really grateful, you know, because... [...] ... she's here to help me because of that same situation because I've lost a baby and she's been a big help. She's the only support that I've had around that sort of situation."*

In another case, a midwife not only remained a constant presence in the mother's pregnancy but also supported her through child protection meetings and an eventual court hearing. There it was agreed that her unborn child would be removed due to domestic violence concerns: *"She was very committed to mine and my baby's needs and very supportive."*

This midwife was present until the birth of the baby, but was not involved when the baby was taken into care at four days old and no further midwifery support was available. The mother did have a routine physical check up with the GP but was offered no psychological support to help her manage her emotions following the removal of her baby. She is now receiving some help to process this trauma. The interviewee implied this was through the NHS but this was not made explicitly clear.

One woman, whose baby was taken into care, described how she felt she might have been offered more support during pregnancy:

*"Thinking of it now I would like to have had proper support really, but thinking of it, I never really got that support to be honest with you".*

### 16. Many women were coping with severe financial hardship

Some problems accessing services through pregnancy and postnatally arose from a lack of basic resources. Most women we spoke to had no transport of their own and limited access to money and support. This led to logistical difficulties in accessing services and an added layer of complication and stress, especially for women facing other needs. One woman was left at hospital without access to money to get home with her baby in the middle of the night:

*"I call the ambulance and the ambulance came and take me. But because I was so confused, I was stressed and didn't take, I was like, it was the night and I was like with this T shirt. I didn't take my bus, the Oyster and I was there and they gave me two hours and got home now. I didn't have Oyster to take the bus. No,*

*we don't pay for you now because you take me with the ambulance so how am I supposed to go home?"*

Another woman described how financial hardship had an impact on her use of services:

*"If I go to the children's centre, I have to take the bus and I can't go every time because, you know, you have to pay money."*

One woman related how, in the middle of the night, she had used emergency services, simply because she did not have a thermometer to monitor her child as she was being advised to.

For many women, financial problems led to hunger and destitution. In some cases, this was managed through help from friends and family:

*"I asked my mum to hold £20 for me for an emergency because I know I will get hungry next week. Yeah, it's really, really tough."*

In other cases, it was clear that skilled midwives, taking the time to understand women's needs and knowing how and where to refer people, could make transformative differences to women's lives.

One woman described financial hardship in her early pregnancy. *"At the point,"* she said, *"I couldn't pay rent and even eating three square meals a day was hard."* She was then referred by her midwife to Linden's Children Centre and received help with basic essentials.

Another woman described how a midwife recognised her weight loss was due to hunger and helped her access food vouchers (this was understood to be NHS food vouchers). However, overall, women felt that it was often wrongly assumed they had access to money and essential provisions.

## Recent migrants, asylum seekers, women who don't speak English and BAME women had specific needs that weren't always met

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### Language barriers

Some of the women we spoke to experienced significant language barriers. This is representative of the area, with a high number of foreign national women in north-east London; indeed 70% of women who give birth in Newham University Hospital, one of the hospitals in the East London Local Maternity System, are born outside the UK. There was mixed reaction to the language support that the women we spoke to were given, and the impact this had on them.

*"It's okay, I know I can speak a little bit but when someone explains better than me then they can take consideration."*

*"Everyone was kind and tried to explain language was a little problem. I was lucky, I got an interpreter when I was first seen but not at the birth."*

*"When I baby born, I leave him for four hours without food because no one tell me you have to food every two hours."*

The language barrier led to some issues regarding consent. Women were not sure of what they were being asked or advised to do. One woman was told she needed to have the "flu jab" during her pregnancy, which she did not want, but she felt coerced because of the language barrier. Another woman had a probe inserted for a vaginal examination during labour, with no explanation beforehand. She considered making a complaint and remains deeply upset about this experience.

One woman recounted that no one explained the caesarean section birth

procedure to her, or helped her to understand the forms:

*“Told to sign forms, didn’t really know what it was about.”*

Where interpretation services were not available, women looked to family or friends they had in this country for help with translation. However, this is not always appropriate, especially with maternity assessments and conversations. One woman only had her 14-year-old son to help her communicate, which she found difficult:

*“Her son helps her to translate ... her son has 14 years”* [then discusses how this isn’t always appropriate].

For several women, confusion around the timings of appointments and services was exacerbated by a lack of English. Some women articulated how hard it can be to navigate a maternity service for the first time:

*“...now I know for the next baby I will be, but when you are new it’s like there are so many things and there are lots of new words I guess for me ... as it’s not my first language”.*

Co-location of services was viewed very positively. Asylum-seeking women spoke about the benefits of services being accessible through their hostels. Midwives visited them routinely at the centres and support staff made appointments with GPs and hospitals to overcome language difficulties.

### **Perceptions of discrimination**

Women were uncertain whether their level of English, or immigration status, was affecting the care they received.

*“The midwife there [at Newham Hospital] are very, very rude...it is all because I don’t speak good English. Because when my friend phoned the hospital and she speak good English, they are nice.”*

*“The way they speak, you know, sometimes I feel like they are ‘okay, you are an asylum seeker, so doesn’t matter very much’, that’s what makes me feeling.”*

*“I was labelled asylum seeker, felt I was last to be seen.”*

*“I think you are left to wait because of where you are from and that should not be.”*

### **Meeting the needs of women related to their religious or cultural backgrounds**

Some of the women felt their cultural or religious views were not properly accommodated or it was not explained why their requests could not be met.

One woman described a male anaesthetist attending her birth despite requesting a female only environment in her birth plan:

*“I wasn’t comfortable with any other man seeing me, but I guess this man did. But I was just thinking to myself, he’s a health professional, nothing is going to happen, you know? I was just thinking, maybe God does forgive me, because initially I didn’t want it. I did write it in my birth plan. But if it’s already happened, that’s not my fault. So, I won’t be punished for that, you know?”*

## Discussion and Conclusions

The policy ambition in England and Wales is that all women should have support to develop and drive their own birth plans, with their input and choice.<sup>21</sup> Our research reinforces this ambition and confirms that women with complex social factors need additional support and care to participate fully in this process. A deep underlying fear and distrust of services, linked to trauma and negative experiences of services made engaging with maternity care and making informed choices in the perinatal period more challenging. Supporting women with multiple disadvantages to understand the processes affecting their choices and to include them fully in decision-making should be valued and prioritised.

The priority under *Better Births* to improve postnatal and perinatal mental health care is particularly critical to improving outcomes for women with multiple disadvantages. Recent evidence has shown that women experiencing multiple disadvantages are more likely to have existing mental ill-health<sup>22</sup>, and more likely to experience perinatal anxiety and depression<sup>23</sup>. Conversely, women in groups shown to be at higher risk from perinatal anxiety and depression are *less likely* to be offered or to access support<sup>24</sup>. Maternal suicide remains the leading cause of direct deaths during pregnancy, or up to a year after the end of it. One in seven women who die in the period between six weeks and one year after pregnancy die by suicide.<sup>25</sup> While it is evident that effective work is taking place, services need to work at identifying issues earlier and offering support for longer periods to more women experiencing mental ill-health.

The need for personalised support and better mental health care is linked intrinsically with the importance of continuity of carer. Our findings bolster the guidance in *Implementing Better Births* on the importance of continuity of carer for women facing complex social factors, and that prioritising this approach with vulnerable women is likely to make the greatest impact on improving outcomes.<sup>26</sup>

Existing evidence shows that women from BAME backgrounds are more likely to experience poorer outcomes and experiences of care.<sup>27</sup> This was important context for our research where the vast majority of women were from BAME backgrounds. This report gives voice to their often-overlooked experiences and their distinct needs.

Finally, where compassionate and skilled midwives effectively identify women's support needs, make swift referrals to specialist midwives and/or to the local expert voluntary and community sector, women and their babies experience much better outcomes. We hope that the findings of this report, and the response to it will ensure that more women who face multiple disadvantage and their babies benefit from the best possible care.

# Recommendations

## Mapping needs and developing structures to meet them

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1. Steering groups of stakeholders working with women with complex social factors in Hackney and Barking and Dagenham should be established to include maternity services; other statutory services such as perinatal mental health and Children's Services; Voluntary and Community Services (VCS) and women with lived experience.
2. The stakeholder groups should review the complex social factors used by maternity services in Hackney and Barking and Dagenham. This list should be extended if it is felt that adding further factors would improve the care offered by maternity services in these boroughs.
3. Current data collection systems should be developed to allow the incidence of co-occurring complex social factors to be recorded in order to determine the extent of multiple disadvantage amongst women giving birth in Hackney and Barking and Dagenham.
4. The stakeholder groups should co-produce a framework and pathway for working with women facing multiple complex social factors in each area. These should specify protocols on the speed of referrals to other services, and incorporate referrals to the voluntary sector; as many VCS organisations in boroughs have capacity and skills to support women; thereby adding value to health services.
5. Access to and investment in continuity of carer for women facing multiple complex social factors should be prioritised by maternity services, reflecting wider NHS recommendations.
6. The number of specialist midwives and teams who work with women experiencing disadvantage (including domestic violence and substance misuse) should be expanded to meet current and predicted future need.

## Upskilling the workforce

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7. Maternity teams should receive mandatory training in order to understand and better meet the needs of women with multiple complex social factors within a trauma-informed framework. Specialist organisations, such as Birth Companions, can deliver this training or work with maternity services to develop in-house training.
8. Within a framework of meeting the needs of women with complex social factors, training should include delivering meaningful routine enquiry; understanding the impact of trauma; supporting the needs of women who have experienced abuse; ensuring respectful care; ensuring confidentiality is maintained and meeting the needs of women with specific religious or cultural backgrounds.

## Families at risk of separation

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9. Maternity commissioners should develop services that meet the needs of women and families in contact with social services who are at risk of experiencing or go on to experience separation from their child. This might be a specialist midwifery role for women experiencing separation, and could combine aspects of existing specialist midwifery roles including those of bereavement and safeguarding midwives.
10. Specialist midwives in this area should be responsible for ensuring families' access to information about support available during the perinatal period and greater transparency about the processes families are involved in. This specialist support should be delivered in collaboration with other services, particularly perinatal mental health, CAMHS, health visiting, social services and those offered by the VCS to ensure women receive the best possible care during pregnancy, birth; and during and in the wake of separation.

## Further opportunities to develop this work

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11. Local Maternity Voice Partnerships (MVPs) should consider working further with the VCS to access the ongoing input and expertise of women with lived experience of multiple disadvantage to inform their work.
12. Work carried out by maternity services as a result of these recommendations should be independently evaluated to explore the impact on outcomes of women and babies.
13. Consideration should then be given to replicating aspects of work found to be effective across the ELLMS area.

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## Endnotes

- 1 In the context of this report, "trauma" was understood to be significant challenges causing deep emotional distress experienced before, or during the perinatal period.
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- 15 Decker, S. H., & Van Winkle, B. (1996). *Life in the gang*. New York: Cambridge University Press.
- 16 Ibid.
- 17 Some of the women had moved from one area to another. For example, two started their pregnancy in other London boroughs and moved to Hackney mid-way through. They did this, for example, to leave a home where there were high levels of drug-use. Four of the women interviewed specifically stated that they were in the last trimester of pregnancy when they arrived in the country as asylum seekers.
- 18 In the context of this report, "trauma" was understood to be significant challenges causing deep emotional distress experienced before, or at the time of, the pregnancy and birth.
- 19 Thomson, G and Balaam, M. (2016). *Birth Companions Research Project: Experiences and Birth Outcomes of Vulnerable Women*. University of Central Lancashire. Birth Companions.
- 20 Ibid.
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